DOCUMENT RESUME

ED 340 184 EC 300 834

AUTHOR O'Toole, Brian John
TITLE Guide to Community-Based Rehabilitation Services. Guides for Special Education No. 8.
INSTITUTION United Nations Educational, Scientific, and Cultural Organization, Paris (France).
REPORT NO ED-91-/WS-6
PUB DATE 91
NOTE 97p.; Also available in French, Spanish, Arabic and Chinese.
AVAILABLE FROM Special Education, UNESCO, 7 Place de Fontenoy, Paris 75700, France.
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS Children; *Community Programs; Demonstration Programs; *Developing Nations; *Disabilities; *Family Programs; Home Visits; Models; Program Evaluation; Program Implementation; *Rehabilitation; Volunteers
IDENTIFIERS *Community Based Rehabilitation

ABSTRACT

This booklet is intended as an introductory guide to community-based rehabilitation (CBR) services in developing nations. The first section examines the magnitude of the problem; the failure of existing services to meet this challenge; and the need for a model appropriate to developing countries. The second section briefly describes the CBR process which stresses the use of home visitors and returning responsibility to the individual, family, and community. Provided in the third section are examples of CBR in practice including programs in Zimbabwe, Kenya, Mexico, Zambia, Philippines, Malaysia, and Guyana. Stressed are the following principles: rehabilitation in response to a locally felt need; acceptance of the concept of simplified rehabilitation; partnership with family members; community involvement; an appropriate infrastructure; and recruitment of volunteers from the community. CBR effectiveness is discussed next showing that the greatest gains came when mothers worked with community volunteers. The fourth section looks at limitations of CBR. Recommendations cover: methods of introducing the innovation; ingredients to help establish sound programs; the need for ongoing training; the role of the home visitor and of professionals; curriculum elements; establishment of parent associations; and the relationship between CBR and institutional-based rehabilitation services. An appendix briefly describes nine programs. Includes 18 references. (DB)

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Guides for Special Education No. 8

Guide to Community-Based Rehabilitation Services

Brian John O'Toole

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Guides for Special Education No. 8

Guide to Community-Based Rehabilitation Services

Brian John O'Toole
Georgetown, Guyana

UNESCO, 1991

ED-91/WS-6

PREFACE

This guide is the eighth in the Series on Guides for Special Education published by UNESCO.

The guides, which are intended for teachers, parents and community workers, aim at stimulating discussions on basic knowledge, approaches and methods relevant to the education of handicapped persons, and offer practical advice for action in this field.

This guide differs from the previous ones in that it addresses an approach to service development. Community-based rehabilitation has received considerable attention during the Decade of Disabled Persons, in particular with the issuing of the WHO Manual 'Training in the Community for People with Disabilities'.

Parallel to that the move away from institution-based rehabilitation prompted governments in developing countries to seek alternative approaches to reach disabled persons and their families.

The UNESCO Consultation on Special Education (1988) recognized integrated education and community-based rehabilitation as two complementary approaches in providing cost-effective and meaningful education and training to disabled persons.

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The views expressed in this guide are those of the author and do not necessarily reflect those of UNESCO.

Earlier topics in the Series:

1. The Education of Children and Young People who are Mentally Handicapped;

2. Working Together: Guidelines for Partnership between Professionals and Parents of Children and Young People with Disabilities;

3. Testing and Teaching Handicapped Children in Developing Countries;

4. Education of Deaf Children and Young People;

5. Language and Communication for the Young Disabled Person;

6. Education of Visually Impaired Pupils in Ordinary School;

7. Community-Based Rehabilitation Services: Prospects, Problems, New Directions.

Special Education
UNESCO
7 place de Fontenoy
Paris 75700, France

1991

CONTENTS

		Page
INTRODUCTION		5
1.	CHANGING TRENDS IN REHABILITATION	7
	1.1 Magnitude of the problem	7
	1.2 Not meeting the challenge	8
	1.3 Need for an appropriate model of services	11
2.	DESCRIPTION OF COMMUNITY-BASED REHABILITATION SERVICES	13
3.	EXAMPLES OF CBR IN PRACTICE	18
	3.1 Rehabilitation in response to a locally felt need	18
	3.2 Acceptance of the concept of simplified rehabilitation	22
	3.3 Partnership with family members	24
	3.4 Community involvement	30
	3.5 In search of an appropriate infrastructure	35
	3.6 Recruitment of volunteers from the community	35
	3.7 The effect of CBR on children and their families	41
	3.8 The establishment of links with institutional-based services	48
4.	LIMITATIONS OF CBR	51
	4.1 Need for an independent evaluation of the concept of CBR	51

Page

4.2 Is CBR a realistic way of closing the gap between need and available provision? 53
4.3 Are the expectations made of the home visitors realistic? 54
4.4 For whom is CBR a relevant approach? 56
4.5 Through what infrastructure can CBR be introduced? 58
4.6 Constraints of working with family members ... 63
4.7 Difficulties in involving the community 67

5. RECOMMENDATIONS 69

5.1 Methods of introducing the innovation 69
5.2 Ingredients that can help establish a firm foundation for such programmes 70
5.3 Need for ongoing training 71
5.4 The key contribution of the home visitor 73
5.5 The role of the professionals 73
5.6 Elements for the curriculum 75
5.7 Establishment of parent associations 77
5.8 Financial investment 78
5.9 Relationship between CBR and institutional-based rehabilitation services 79

6. CONCLUSION 82

APPENDIX - Examples of CBR programmes from around the world 85

REFERENCES 93

INTRODUCTION

The following booklet is intended as an introductory guide to community-based rehabilitation (CBR) services. The booklet examines a number of CBR projects across the world and attempts to examine both the assumptions and the strength of the approach. An attempt has been made to adopt a narrative style. For a more academic analysis the interested reader is directed to references given at the end of the booklet.

The writer acknowledges a real debt to a number of persons in this area who have assisted in either reviewing earlier drafts of the booklet or who have provided the writer with ideas and materials over the years. These people include Professor Peter Mittler, Professor Pam Zinkin, Dr Brahm Norwich, Dr Roy McConkey, Geraldine Maison-Halls, Mike Miles, Lilian Mariga, Caroline Arnold and David Werner. The support, encouragement and guidance of Lena Saleh of UNESCO in producing this booklet is also gratefully acknowledged.

1. CHANGING TRENDS IN REHABILITATION

1.1 Magnitude of the problem

A series of international reports estimate 10 per cent of the world's population to be disabled. Surveys in developing countries have suggested this may even be a conservative figure. The Zimbabwe National Disability Survey, for example, based on in-depth interviews conducted in 23 different locations by specially trained personnel, identified 15 per cent of the population as disabled. Moreover, a total population survey of the children aged 5-14 years in one village in Nigeria revealed 25 per cent of the population as having some form of handicap.

The precise numbers could be debated; however, the need is clear. Disability creates a considerable social, economic and emotional cost to the disabled person, their family and the wider community. The burden falls disproportionately on those in the developing world where disabled persons often live without dignity, victimized by beliefs that they are possessed by evil spirits or proof of divine retribution.

An estimated 75 per cent of the disabled population live in developing countries; however, if the present trends of poverty, ignorance, superstition and fear continue the figure may rise to 80 per cent by the end of the century.

The present model of rehabilitation, based on institutional care, would absorb more than the total health budget of most developing countries if serious attempts were made to meet the needs of all disabled persons. Is it

therefore realistic to expect poorer countries to direct scarce resources to expensive services for a minority?

If the developing world is to give a higher priority to disabled persons it must be in the name of a just society; no nation can morally or practically ignore a problem affecting such numbers. The danger is that rehabilitation may be given a low priority because the goals of overcoming pain, suffering and dependency cannot be easily quantified. Misery cannot be tolerated simply because it is not easy to measure. Morally, governments have to respond; however, for practical reasons more economical approaches will need to be explored to meet the magnitude of the task.

1.2 Not meeting the challenge

It has been estimated that existing services are reaching no more than 2 per cent of those in need. Rehabilitation is regarded as inaccessible in rural areas. The international situation is thought to be no better now than 25 years ago.

This bleak assessment is based on reports from all corners of the developing world where the available rehabilitation facilities are concentrated predominantly in urban areas.

The International League of Societies for Persons with Mental Handicap (ILSMH) carried out a continent-wide review of the coverage of special schools of children with specific learning disabilities or mental handicap. The figures recorded were: Nigeria 0.7 per cent, Zambia 2.9 per cent, Botswana 4.7 per cent and Kenya 4.5 per cent. Moreover, these figures were regarded as 'rather generous estimates'.

The pattern is the same in Asia. Surveys in Pakistan, Indonesia and the Philippines revealed that a very small percentage of the population had access to the nation's rehabilitation services which were based in the cities. The situation with the visually impaired in the Philippines illustrates this point. The number of blind persons in the

Philippines is estimated at 850,000 and yet the sole provision, four rehabilitation centres based in urban areas, can cater for only 100 persons annually (Berman and Sisler, 1984).

A comprehensive survey of 33 countries, representing half of the world's population, identified 14 million physically handicapped persons of which one in six needed some form of special equipment. However only 1 per cent had any form of aid at all. The international picture is therefore bleak; indeed, in some places, where 'help' is available it may be nothing more sophisticated than the wearing of ornaments to ward away evil spirits. The ornaments symbolize the mechanistic approach adopted in attempting to meet the challenge.

The international strategy in health has been to create relatively sophisticated services staffed by highly qualified personnel with the hope of expanding them progressively as resources increase until the whole population is covered. The reality has been very different. Services have become centred on urban areas accessible only to a small and privileged section of the community.

The situation regarding rehabilitation is even more serious. In light of the millions of persons in need, the prevailing institutional-based model of rehabilitation has come under severe criticism. The undue concentration on an urban élite, the adoption of unnecessarily high standards of training, the narrowness of specializations and the isolation from normal life are some of the criticisms levelled at the institutional-based approach.

The limitations of the institutional-based model are also apparent in the West. Twenty-five per cent of North Americans live in towns with a population of 2,500 or less. For the disabled persons in these areas there is obviously less opportunity to make use of the wide range of services found in the cities. Greenwood (1985) estimates that only 15 per cent of the disabled population in rural America get any professional help. He stated: 'there is no evidence of any

impact of rehabilitation services on these rural disabled persons'. The situation may be no better in the cities. It has been estimated that only 2 per cent of stroke patients in Los Angeles receive comprehensive rehabilitation.

Despite the lack of services an apparently paradoxical picture emerges in developing countries where people turn their back on free health services and where there is a significant under-utilization of the available resources.

A sophisticated rehabilitation centre outside Lusaka, in Zambia, attracted only 10 per cent of those in need, despite the offer of free transportation. A survey of the physiotherapy facilities in a 120-mile radius of Ibadan, one of Africa's most populous cities, revealed that only 53 children were receiving treatment. Attempts to set up rehabilitation services in rural areas of Mexico have sometimes proved unsuccessful as the mothers did not take advantage of the services.

The same pattern of under-utilization is evident in the West; despite the array of services provided there appears to be little reflection whether the services offered are what families actually want and need.

The low utilization is especially apparent in certain sections of the community as a result of dissonance between the cultural orientation, values and expectations of service providers and potential clients. Such a pattern is evident amongst rural populations in developing countries, minority groups in North America, and the working classes and immigrant population in Britain. The very persons in need of services are the least likely to seek out help. Some method therefore needs to be found to make the services relevant and accessible to rural and minority groups.

For those who do use the institutional-based services, many leave dissatisfied. Parents often remain confused concerning the precise objectives of the various therapists and educators they encounter. Hospital visits are often

unhelpful, characterized by long periods of waiting only to be faced by the uncaring attitude of the doctor. Similar experiences have been observed in parents dealing with large social-educational institutions for handicapped children. There have been many examples of frustrations experienced by families dealing with the 'helping professions'.

A major reason for lack of progress in this field can therefore be attributed to the concentration on the institutional-based model of service delivery internationally.

1.3 Need for an appropriate model of services

One reason for the lack of progress is that the professional roles which are adopted are inappropriate to the needs of developing countries. Services in developing countries are often patterned on an inappropriate Western model, including intensive overseas training only to result in the therapist returning home with an expertise which is often too sophisticated to apply and which is unsupported by the technology to which they had grown accustomed.

We have been seduced by the modernization mirage which has fostered the illusion that Western skills, knowledge and attitudes should be diffused to developing countries. The mirage is so vivid that many civil servants insist that Western-style institutions are the solution and anything else is 'humiliatingly second-rate'. In our blinkered desire to imitate the services offered by the West we have lost sight of the true magnitude of the problem. The justification for the focus is the need to 'maintain standards'. However, to the 98 per cent of families who are presently receiving no assistance the argument concerning 'standards' has no relevance. For them the question becomes, quite simply, will any significant service reach them during their lifetime.

The 1980s witnessed a change in thought and action concerning development with a movement away from a top-down model of service delivery. Previously social service programmes for rural communities and marginalized urban areas

have been planned and implemented by bureaucratic institutions without the consultation and involvement of the intended consumers.

There is a growing realization that if the subjects of development do not participate actively in the relationship with those who would promote the development process, change will be impossible. There is a significant gap between the potential and practice in the area of disability. One reason for the gap is that volition is a prerequisite of action. The active participation of the subjects of development at all phases of the development process is essential. One of the basic questions now becomes: how can we guide individuals who, for so long, have traditionally been led by others, to take charge of their own affairs? We need to move away from regarding rehabilitation as a product to be dispensed, to offering rehabilitation as a process in which the villagers are intimately involved.

2. DESCRIPTION OF COMMUNITY-BASED REHABILITATION SERVICES

The 1969 meeting in Dublin of the International Society of Rehabilitation (now Rehabilitation International), voiced some of the first public misgivings concerning the institutional-based model of rehabilitation. The experts noted the significant disparity which existed between needed services and available provision and acknowledged that the gap could not be closed by developing conventional services. It was recognized that the pace at which personnel were being trained was not adequate to meet the current problem. There was a realization of a need to identify new forms and patterns of services which required fewer professionals, less advanced forms of training, simplified methods of rehabilitation and which could facilitate an expansion of the existing rehabilitation provision. Questions were asked concerning methods of providing the most essential assistance to large numbers of persons utilizing readily available resources. The need for an innovative delivery system was recognized and the World Health Organization (WHO) recommended the provision of essential services and training for disabled persons through community-based rehabilitation (CBR) as part of the 'Health For All' campaign.

The emergence of the concept of primary health care entailed the acceptance of two important principles which had been vigorously resisted earlier. Firstly, that it is more important to bring about even small improvements among the entire population than to provide the highest standard of care for a privileged few. And secondly, that non-professionals, with limited training, could provide crucial services.

The World Health Organization has provided the stimulus for incorporating rehabilitation into primary health care with the publication of a manual, Training the Disabled in the Community (Helander, Mendis, Nelson and Goerdt, 1989). The World Health Organization initiated the first version of the manual in 1979. Its dissemination and use in about 60 countries in the last ten years has facilitated the promotion of this concept.

Whilst the World Health Organization has done much to pioneer the development of CBR one needs to appreciate the breadth of the concept of rehabilitation. A WHO Expert Committee gave the following definition for 'rehabilitation': '... combined and co-ordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest possible level of functional ability' (ref. UNESCO, 'Terminology of Special Education', 1983). There is a need therefore to widen the perspective of CBR from being strictly seen under the umbrella of primary health care and move towards encompassing other sectors of community services. The regular school will increasingly play a major role in this respect and definite efforts need to be exerted to prepare the regular class teacher to perform this role effectively. In many instances it may be left to the class teacher to combine and co-ordinate the various aspects of service provision for the child and their families. There is a need for greatly improved communication between the different partners in the rehabilitation process. The lack of such a partnership is the frustration experienced by many persons in this area. An appreciation is needed that all partners are equally important, but play different roles and often at different stages. Often the identification of disability will be made by persons from the health and social services. However, once the child reaches school age a major question for most parents becomes educational provision. In a similar way a later demand will be for some kind of vocational training.

The 1988 'UNESCO Consultation on Special Education' underlines how much needs to be done in this area. Of the

51 countries supplying information on special education provision, 34 acknowledged that they had provided for the needs of fewer than 1 per cent of pupils. Moreover, the major form of provision was in special schools.

With a realization of the magnitude of the problems and with a growing appreciation of the principles of normalization, integration and participation there is a major role to be played within the regular school system. The education and training needs of the majority of disabled persons cannot be met by special schools and centres alone.

Just as there have been radical changes within the health field with the development of primary health care so too there needs to be fundamental change in the area of special education. Special schools, as the 1988 UNESCO report suggests, could be used as resource centres for outreach programmes, providing in-service training for ordinary teachers, outreach support services for families and disabled children, or providing educational support to children with special needs in ordinary schools. The UNESCO document concludes that integrated education and CBR therefore need to be regarded as two complementary approaches in providing cost-effective and meaningful education and training to disabled persons. An effective partnership needs to be established and developed between these two vital components if meaningful progress is to be achieved in the coming decade.

Rehabilitation has, however, traditionally been based on buildings, equipment and professionals. A sacred aura has developed 'such that persons in developing countries are led to believe that anything else is unacceptable'. Previously the individual and the problem were lifted out of the social context in which they existed and attempts were made to impose a solution in a new context of the therapist's making.

Most disabled persons live in rural or marginal urban communities. Rehabilitation is therefore best done in that environment with the child's care-givers as the primary

training agents. The family therefore needs to learn what to do to help and requires a system of support and encouragement.

The goal of CBR is to demystify the rehabilitation process and give responsibility back to the individual, family and community. A home visitor is recruited from the community and trained. The home visitor could be a health worker, teacher, social worker or volunteer. The home visitor shows a member of the family how to carry out the training programme.

Those with the highest motivation for helping children are the parents themselves. Parents generally care for their children and want them to attain their maximum potential. When the child is taught in her home and reinforced by her parents it is more likely that learned behaviour will generalize and be maintained, a major problem for handicapped children.

Working in the home affords direct and constant access to the full range of the child's behaviour as it occurs naturally. Many aspects of the behaviour cannot be targeted for modification in the classroom alone. Increasing the parent's ability to manage and train their own children lessens the risk of poor parent-child relationships and produces psychological gains in the parent which will benefit younger and subsequent children. Moreover, in pursuit of the philosophy of normalization, it is logical that the intervention be offered in what is obviously the least restrictive environment, the home.

CBR is based on simplified methods of rehabilitation which, in the World Health Organization scheme, are described in a series of booklets. CBR should use existing organizations and infrastructure for the provision of services. Simple tasks are therefore delegated to auxiliaries or volunteers whose performance is supervised by an intermediate-level supervisor.

CBR should involve the community in the planning, implementation and evaluation of the programme. Links are established with higher referral services to cope with more specialized needs. CBR is an attempt to generate an increase

in appropriate skills, distributed to where the needs are, by utilizing hitherto unexploited resources in the community.

Social change is needed to pave the way for greater effectiveness in this area. Such transformation is only possible once the family and the community take responsibility for the change. Community involvement in rehabilitation therefore is a process which needs to be nurtured and facilitated. It is not simply rehabilitation done at the community level but rather rehabilitation as part of the process of community development whereby the community seeks to improve itself. Only when this happens does social integration, full participation and equality of opportunity have any meaning and become realistic goals. Once the community takes on responsibility for the rehabilitation of their disabled persons then the process could be called community-based rehabilitation. To achieve such goals the necessary knowledge and skills need to be made freely available in the community. In such a process rehabilitation becomes one element of a broader community integration effort for disabled persons.

3. EXAMPLES OF CBR IN PRACTICE

3.1 Rehabilitation in response to a locally felt need

The rationale for CBR has largely been established on a series of international reports which highlight the magnitude of the problem of persons with disability and which stress the inadequacy of institutional-based rehabilitation facilities in meeting the pressing needs. However, it is debatable whether any reliable surveys have been carried out in developing countries to ascertain the precise magnitude of the problem. There is widespread reluctance to co-operate with such surveys, e.g. surveys in Botswana and Mexico were stopped because of the perceived futility of counting heads when no services were available. The available figures may only be symbolic of the size and scale of the problem rather than being anything even approaching accurate estimates. There may also be a danger that in quoting high incidence figures international organizations are making the classical mistake in development of defining others' needs for them. It is worth considering how many of the 10 per cent would regard themselves as disabled or would be thought of as disabled by their families. The label 'handicapped' in the context of a developing country may be better reserved for those for whom differences amount to a severe life problem.

In practice, repeated visits have to be made to rural communities before parents admit to having disabled children. Once parents see tangible help being offered to others in their position they will seek assistance. It is not difficult to appreciate the lack of interest in mothers in simply having their child counted by a researcher. The identification of

disabled persons in a community cannot therefore be a static event.

The effective programme in Zimbabwe (Mariga and McConkey, 1987) grew out of a recognition that the existing services were not meeting the present needs. The rural outreach programme was organized by Zimcare Trust who were responsible for the education and training of the mentally handicapped persons in the country. Their 15 centres, employing 300 staff, were catering for only 900 handicapped persons. The National Disability Survey estimated there to be 27,000 mentally handicapped persons in Zimbabwe (Madzima, Matambo and Else, 1985). The survey revealed the complete isolation of the great majority of these persons. The infants were often ignored and given no stimuli. When the families were asked how many children they had, the disabled child was often excluded from the total. However, with the establishment of universal primary education, publicity from the various rehabilitation programmes and the formation of Zimcare Trust there was a significant increase in the demand for services in Zimbabwe. Zimcare recognized that more centres were not the solution and therefore began an outreach programme to help disabled persons within their own communities. The programme was an attempt to serve the previously unreached persons who had very limited access to facilities and whose problems were often so severe that the existing facilities would have very little to offer them. Now, with demonstrable success, the programme is being expanded to other outlying areas.

In Kenya, Arnold (1986) estimated there to be 200,000 mentally handicapped persons. However, only 400 children were being served in special schools. The Family Support Service for mentally handicapped children grew out of a local self-help group who ran a small school in the capital and who realized the need to move out into the rural communities to meet the needs of disabled persons in outlying areas. The plan was to move out from the urban base into rural communities to multiply the effects of the school by developing support services for the families. After about six months of the project the parents began to see what their child was capable

of achieving and became more vocal concerning their demands for an extension of services. The programme is now being used as a training base for the outlying areas. The project therefore demonstrated what could be achieved through existing resources with a modest enrichment of training programmes for health, welfare, educational and vocational services.

Project Projimo in Mexico (Werner, 1987) grew out of a village-run rural health care service, called Project Piaxtla. In their work as primary health care workers the needs of disabled persons became very apparent. The health workers came together and presented a rehabilitation plan to the community. Project Projimo is now in the process of training persons from other villages to undertake similar projects. A number of satellite centres have now been formed with the goal of giving the family the understanding and skills they need to help disabled persons reach their full potential.

In 1983 in Zambia a campaign was launched to reach the disabled children of the nation. The goal was to establish the foundation of nationwide services. Attempts were made to develop a screening programme in the 57 districts of the country and to create 3,000 reporting centres as a means of assessing all disabled children between the ages of 5 and 15 years. Each district was to establish a rehabilitation team with multidisciplinary members from health, education and welfare to create a care plan for each disabled child. In every province a specialist team was to be created to check the diagnosis, arrange for any necessary operations, drugs, aid and offer in-service training.

In the Philippines, Valdez (1984) and Periquet (1984) describe the dialogue conducted with barangay leaders to help sensitize the community to the needs of disabled persons in their midst. The consultation helped gain the support of local politicians who were made to feel part of the programme.

In Malaysia, the Society for the Blind acknowledged the low provision for visually impaired persons in the country and

therefore mounted an outreach programme. The existing institutional-based provision was meeting the needs of no more than 80 visually impaired persons per year (Jaekle, 1986).

In each of the above cases therefore the programmes were introduced as a response to a locally felt need.

One of the objectives of the Guyana CBR project (O'Toole, 1990) was to ascertain the size of the problem of disability in a rural area of Guyana. A systematic survey of one village was therefore carried out by participants on the CBR programme and members of the community. The local community was well prepared for the exercise with widespread publicity in the media. A local committee had begun to make plans to establish a school for the disabled children of the village. It was therefore clearly understood that the survey was not merely an academic exercise but had an immediate practical purpose. Four thousand six hundred persons were surveyed and the incidence of disability was found to be 1.9 per cent. Thirty-three children in the village had problems that were severe enough to significantly impede their daily living. Ministry officials requested meetings with the survey team to discuss the findings and to review possible courses of action. The survey results were used by the National Rehabilitation Committee as evidence to support their advocacy for the creation of a school in the rural area. The survey therefore demonstrated a need. The community's participation and the response of the Ministry of Education indicated an appreciation of the problem within the country. As the programme continued more and more children were referred to the project and requests were received from other regions of the country to run CBR programmes in their districts suggesting that the needs of disabled persons can be regarded as a priority once it can be demonstrated that something tangible can be done to help them.

The same pattern was evident in Zimbabwe (Mariga and McConkey, 1987), Kenya (Arnold, 1986), Indonesia (Johnson and Tjandrakusma, 1982) and Pakistan (Jaffar and Jaffar, 1986). In

this sense CBR became a locally perceived need and outreach programmes were organized as a definite response to the need.

The CBR programmes therefore helped to raise the consciousness of parents of disabled children, community organizations and ministry personnel to the need for services for disabled persons in rural areas.

3.2 Acceptance of the concept of simplified rehabilitation

Even if the rehabilitation of disabled persons is perceived as a need by the rural community one needs to examine whether the simplified model of rehabilitation offered by CBR is regarded as a viable response.

In a one-year follow-up by independent evaluators of the Zimcare programme (Madzima, Matambo and Else, 1985) only 1/136 mothers found the programme to be unhelpful. In endorsing the model of simplified rehabilitation the parents recorded their appreciation of understanding the child's problem more and noted the obvious improvements in the child. The rapid expansion of the Zimcare programme is testament to the relevance of the concept of simplified rehabilitation in a Zimbabwean context.

In Malaysia the families had high praise for the programme with rural blind persons (Jaekle, 1986). The independent evaluators recorded the excellent rapport between programme personnel and the families of disabled persons and blind persons themselves. The evaluators judged this caring relationship to play a significant role in the programme's effectiveness.

An independent evaluation of Project Projimo (Villegas, 1985), observed that 95 per cent of the parents gave the programme high ratings. Eighty per cent of the parents felt they had a good understanding of the physiotherapy exercises. Eighty-five per cent felt more hopeful concerning their relative's future after attending the project. The parents particularly appreciated that services were free, the fact

that parents were highly involved in the rehabilitation, the time they were given by the project workers, the comprehensive examination and the dialogue with team members.

In the Kenyan experience (AMREF, 1987), the programme was regarded as a major step out of isolation for the families. The home visitors were judged to be committed to the project and were well accepted by the parents.

The CBR services in the Philippines (Berman and Sisler, 1984) worked in six regions of the country, each of these was reaching more clients annually than all the residential services in the Philippines combined.

Very few of the children on the Guyana CBR programme had been exposed to institutional-based facilities before the project began. Of those who had made contact none were able to continue to benefit from the provision at the outset of the CBR programme. Three of the mothers commented quite simply that the child was now too heavy to be carried on public transport. Even though the services were freely available only a few miles away, the practical problem of getting the child to the services was too great an obstacle. The other family that had contacted institutional-based services had left, disillusioned by long waits for missed appointments by doctors and specialists.

In evaluating the Z ·ian CBR services, Serpell (1986) acknowledged the often in equate preparation of home visitors and the limited supervision and training that was offered but concluded simply that if it was not for the CBR service, the disabled persons in the rural areas would get no provision.

The joy on the face of a cerebral palsied boy who is taking a few 'steps' with his legs reinforced with splints made out of rolled-up newspaper and cloth is one of the engaging shots on the video, 'Step by Step' (O'Toole, 1988) which documents the Guyana programme. The modest splints were sufficient to strengthen and support the child's legs. A series of simple exercises helped to stimulate the child's

sense of balance. The video shows the boy seated on the arm of a chair, rocking side to side to get the feeling of movement and balance. Simple toys were placed on chairs to stimulate the child to stand up and support himself.

The Guyana CBR programme proved acceptable to the key administrators in the area. All the relevant professionals accepted invitations to participate in the programme as resource persons. The mothers almost unanimously welcomed the presence of the home visitors. The concept of simplified rehabilitation therefore proved acceptable to the administrators, the rehabilitation therapists and the parents.

Within the various projects therefore a number of disabled persons clearly responded to the simplified rehabilitation which the CBR programmes offered. Many of the parents began to see what could be used in their everyday environment to help the child acquire the next developmental task. Simple games were often suggested to offset the tedium of the day for many of the children with special needs. There will of course be others who need referral to more specialized help. The success of this referral process will be explored in a later section.

3.3 Partnership with family members

There are many parents who would not be able to relate to the pessimistic statements in the literature on the impact of a handicapped child on the family. The stereotypes of guilt, shame and depression are simply copied from one report to the next.

The literature tells us nothing about what it is like to have a disabled child in the family, but a good deal about other people's ideas of what it ought to be like. Anything parents have said or done has been used in evidence against them. When writers talk about 'pathogenic attachment' or the 'too cohesive family' it seems that genuine love and concern cannot be admitted. If parents make allowances they are 'over-protective', if they attempt to minimize the disability

they are 'failing to accept the situation'. Too often researchers have fallen back on their psychological ancestry to analyse the data.

By contrast many families manage to adapt to having a handicapped child. Indeed, in some cases the birth of a handicapped child brings the whole family closer together. One of the parents in the Guyana study stated that the CBR programme had helped his family learn how to work together as a unit. The disparity in the literature is simply a reflection of the variability which exists between parents with different degrees of capability, time and energy in dealing with their children.

For practical reasons of unemployment, poverty or ingrained attitudes, there are families where involvement is unrealistic; however, for each of these cases there are as many others who are eager to become involved once they are given the necessary support, information and guidance.

For some of the parents on the Guyana CBR programme the lack of progress on the child's part was not sufficient to merit the parent's concern. A typical response to a child with speech problems was 'he gan speak when he ready'. Others felt threatened and defensive, feeling their ability as guardians was being questioned. Some were discouraged by long years without any apparent progress. The disunity of some homes prevented any consideration of the needs of the disabled child. Poverty was a real problem for the single parent. In being forced to go out to work the child was often left alone or in the care of an older sibling. In such cases there was simply no one available through whom the home visitor could work. However, whilst for some the role of involvement was too demanding there were as many others who were deeply involved in the rehabilitation of their children.

Parents do want to help; however, they may not always know how to proceed. Parents invariably emphasize the need for practical information, support and advice.

Satisfying parents' emotional needs may, however, be a vital first step in helping the parents come to terms with the way they feel. Parents stress the need to have someone to talk with, to help overcome the feelings of shame and guilt. What parents valued most was knowing there was someone to whom they could turn at any time. Parents do want assistance; however, their major need is in the affective domain. Highly child-focused, cognitively oriented programmes may not be responding to the parents' needs.

In analysing the relevance of the concept of parental involvement to the context of a developing country at least three prerequisite skills need to be examined:

(i) Understanding the child: an appreciation that children develop skills in an orderly sequence which is relatively universal.

(ii) Belief in teaching: the belief that child development can be accelerated by intervention and that parents can play a key role in this respect.

(iii) Opportunities for teaching: the acceptance by the parents that changing the environment or their approach could help the child learn.

An attempt was made to examine the above questions by asking 137 Guyanese mothers to complete a questionnaire (O'Toole, 1989).

The questionnaire was administered by 12 interviewers trained by the researcher. The concept of ages and stages of child development was further explored in a study of 31 Guyanese mothers. Each of the mothers was given a series of 104 cards; one of the Portage checklist items was written on each card; every fifth item from the original checklist was used for the study. The items were presented in a random order and the mother was asked to sort the cards according to the order in which a child could be expected to acquire the skill.

(i) Understanding the child

The mothers had no difficulty with the sorting of the Portage checklist items. The concept of looking at child development in sequence presented no problems. The items were sorted separately according to area (i.e. motor, cognitive, self-help, socialization and language). For each of the areas there was a high correlation between the original Portage developmental sequence and the sorting made by the Guyanese mothers.

The results were therefore consistently in accordance with the original Portage development sequence and revealed that mothers did have a conception of the child's development proceeding in stages and that the stages were comparable to Western norms.

The questionnaire asked 137 mothers a series of questions concerning the ages at which children normally acquire certain developmental tasks such as the age at which a child would walk, dress or feed unaided.

The overall agreement with Western norms was 50 per cent. The disagreement concerning certain ages is perhaps less important than the fact they do appear to share the concept of ages and stages of development.

(ii) Belief in teaching

The mothers were asked a series of questions concerning whether the child could be helped to achieve certain developmental tasks such as being able to learn to talk, walk or feed on their own. Eighty to 90 per cent of the parents agreed the child could be helped to achieve such tasks.

In each case a number of plausible and realistic teaching suggestions were given to help the child acquire the various skills. Mothers do therefore have the belief that the child can be taught to acquire early developmental skills and that they can play a key role in this process.

(iii) Opportunities for teaching

Even if parental involvement is culturally appropriate one still needs to assess whether it is a practical proposition in developing countries. Whilst the questionnaire suggests that certain prerequisite skills necessary to introduce a parent involvement programme clearly exist, it also revealed serious practical constraints in performing such a role. Twenty-four per cent of the Guyana sample represented single parents. The fathers' role in the other homes was minimal. The parents were asked concerning a number of housekeeping tasks within the home. Fifty-one per cent of the tasks were done by the mother alone; less than 1 per cent of the roles were performed by the father alone. The burden of the home is clearly on the mothers' shoulders; their ability to put aside specific periods of time to 'teach' the child would need to be considered carefully. Creative ways need to be investigated in which assisting the child's development becomes an integral part of the mother's day rather than making unrealistic extra demands on an already overburdened individual.

It would therefore appear that the philosophy underlying parental involvement is not alien to the context of a developing country. At the same time real practical constraints are also apparent.

Some parents may enthusiastically embrace the teaching role; for others the role may be too demanding. It would be valuable to investigate the variables within the child, family and community which contribute to effective programmes.

At least half of the parents in the Guyana project welcomed the role of greater involvement in their child's rehabilitation. For them the goal was not to add one more demand on an already overburdened parent but rather to assist in improving the quality of the interaction between parent and child in the time that was available. The great majority of the mothers who completed the training programme in the Guyana project felt they had played a key role in the project.

A number of variables which could influence the effectiveness of a parent involvement programme were examined. The major variable appeared to be the parent's desire to help the child. Other factors, such as family size, income levels, educational background of the mother and the severity of the child's disability, did not appear to be as crucial determinants of the success of the programme as the mother's attitude towards her child and her involvement in the programme.

There is obviously no simple prescription for involvement. In a number of cases in the various projects it was evident that severe practical problems prevented the family from becoming fully involved, some were real material difficulties and others were perhaps barriers of their own making. Some parents who came from similarly disadvantaged backgrounds played major roles within the project. In some of the motivated families the mother was able to draw support from an extended family network, in others, single mothers struggled valiantly to do what they could to assist their children.

The danger of pushing parents further apart by focusing on the mother-child relationship was reviewed earlier. It should be noted, however, that the father's role is traditionally limited in developing countries. Parents may well already have a role division with which they are both content. The present routine may well have its own momentum which could be threatened by suggesting unrealistic changes. A balance therefore needs to be achieved between encouraging parents to avail themselves of the opportunities provided and feeling pressurized into conforming.

An appreciation of the different ways families lead their lives is necessary; if such considerations are overlooked the danger is that CBR may be no more effective than previous approaches in meeting the family's needs. An essential part of the flexibility is the recognition that parents may not want a role of active involvement in the project. The goal therefore is flexibility in responding to the needs of each family

rather than prescriptions of developing services on one model. The element of choice should be preserved and sweeping generalizations of what parents 'need' should be avoided.

3.4 Community involvement

There have been few well controlled studies concerning attitudes towards disabled persons in developing countries. Much of the literature is impressionistic and anecdotal.

Community attitudes vary a good deal more than some reports would suggest. They vary not only across societies but also within them and between adjacent neighbourhoods. Some writers have argued that there is less prejudice towards disabled persons in developing countries. In some societies mentally handicapped persons are believed to possess a 'saintly touch'. Some North African groups regard families with handicapped children as 'especially favoured', the logic being that God would only select devoted, loving families to receive a handicapped child. Whilst the above could be criticized for being impressionistic, anecdotal and dated, it does at least help to balance the uniformly negative picture presented in some reports.

The attitudes may therefore be a little more enlightened than was suggested earlier. Moreover, there are examples in developing countries where the community has been deeply involved in rehabilitation projects. Kgosana (1984) reports a high degree of community involvement in Sri Lanka where a committee, composed of village elders met monthly to monitor the project. The handicapped persons became the shared responsibility of the community.

The very name of the project in Mexico, 'Projimo', means 'good friend' or 'neighbour' in Spanish. The leaders of the community were interviewed and all were found to be involved in some way with the project (Villegas, 1985). Project Projimo is run by disabled persons themselves, the great majority of whom are Mexican nationals. As a result of the programme the disabled persons gained the confidence to move about the

village more. A series of child-to-child activities in schools helped to raise the children's awareness of the needs of disabled persons. Programmes were developed in schools to help children learn concerning the health and social needs of others by, for example, taking turns to act out a form of disability. Street theatre also illustrated the needs of disabled persons in a way that the villagers would remember. An initial success in promoting involvement was the creation of a community playground built by disabled persons and others from the village for the benefit of the whole neighbourhood. As a result the disabled persons in the area are simply considered as an integral part of the community (Villegas, 1985).

In Burma (WHO, 1982) a high degree of local involvement in the programme was achieved through a process of effective dialogue with the village leaders and extensive propaganda.

The CBR programme in the Philippines (Valdez, 1984) was widened to encompass mini-Olympics, field trips, leadership training seminars and cultural programmes. By effectively co-ordinating government and private sector contributions the community was significantly involved in the project. A major key to the motivation of the home visitors in the Philippines was the recognition given to them by the community. Periquet (1984) judged the social link of the home visitor to the community to be a major asset and one which helped offset their less than complete professional training.

Community involvement is repeatedly exhorted in the literature. However, it is usually unclear as to what it means. What channel does the community have to express itself? How can the community feel in control of the programme? How can the community become involved? The co-ordinators of innovations are often high in technical skills but relatively naïve in terms of organizational, social and political skills. Promoting community participation is therefore a skill which co-ordinators need to learn. Many innovations, which may themselves be effective, have limited long-term impact because of the lack of any real involvement of those concerned. The

participants and decision-makers remain unaware of the potential value of the innovation.

The traditional approach is often characterized by one-way directions; the community is never truly involved in the implementation and planning of the programme. Communication becomes an act of making deposits into empty containers, it becomes a dehumanizing and patronizing experience for the recipients, any gains are only short-lived, the programme rarely becomes self-sustaining.

Such participation cannot be brought about by political decree from the top. People will become involved only if they feel genuinely consulted concerning their needs. The goal of development is to influence people, not simply to modify structures. Effective dialogue may be the key, whereby the community learns to solve problems for themselves.

Training needs to focus on the method of facilitating consultation, developing management skills and becoming a sensitive listener. The effective co-ordinator sits with the local workers, listens and respects their plans. Suggestions may be offered but it should always be clearly understood who the key actors in the process are. The co-ordinators need a belief in the people. The faith that they can solve their problems with a minimum of outside assistance needs to be communicated to the villagers.

The theory of participation is that the community should be involved in the planning, implementation, management and evaluation of the programme. The reality, however, is usually that the community passively accepts external decisions. The co-ordinators need, however, to perceive their role to inspire and advise, not to make unilateral decisions, to assist the home visitors and parents in coping more adequately with their own problems.

We should never create something which cannot be locally self-sustaining. Innovators need to believe that villagers have within themselves most, if not all, the ideas, resources

and energy to bring about change. The outsider's role is a facilitative one with temporary infusions of aid or technical assistance, such inputs are mostly peripheral to the real change process. Great care needs to be exercised to avoid dependency on the home visitor. The responsibility for the child remains with the parents and is not taken over by the helper. In an effective programme villagers will become more aware of resources which exist in the community and will begin to effectively utilize these services.

One of the encouraging features of the Guyana project was the level of community involvement that was generated. The radio and newspaper coverage did much to help enhance the prestige of the programme and began the process of community awareness. It was appreciated that an effective innovation requires a well-informed community, time was therefore given to preparing the community in this way. The ongoing involvement of the nation's leading rehabilitation therapists and the Parents' Association of Disabled Children ensured broad-based support for the project and warned away potential critics of the programme.

The local and international financial support gave the home visitors an important psychological boost in thinking that they were working on something significant. This feeling was enhanced by the presence of the Mayor and leading figures from the university, the Ministry of Education and the Ministry of Health at public meetings co-ordinated by the participants of the programme.

The Village Health Committee which was formed by home visitors and parents from the project became an articulate advocate of the needs of disabled persons. They played a major role in preparing the community for the survey, mobilizing persons from the community to participate in the interviewing and in presenting the results and recommendations to the Ministry of Education. The committee met with a local Hindu organization and signed a contract for a two-year lease on a building which housed the school. The building was offered free of charge by the Hindus, and a number of local

organizations participated in modifying the hall into a school for disabled children.

Many of the problems of disabled persons are not because of the disability but the attitudes of others around them. A number of attempts were made as part of the programme to help overcome the feelings of powerlessness, pity and despair that disabled persons evoke in others. These efforts included: film shows, panel discussions, public meetings, articles in newspapers, radio talks, lectures in schools and the production and showing, five times, on national television of a 30-minute video on the CBR programme. In addition the home visitors, on their own, organized two three-day workshops for parents of disabled children.

The home visitors organized transportation, food and equipment. Materials were donated by a host of local companies. It proved to be an imaginative and creative use of what was available within the local community. The workshops focused on demonstrating teaching ideas to the parents and giving children, some for the first time, outings to the zoo and park. Many barriers were broken down in these workshops and a number of parents began to see something of what could be done with their children.

Whilst one needs to be sensitive to local attitudes it is all too easy to postpone action with the noble rationalization that the community is 'not yet ready'. A balance needs to be achieved between moving too fast and too slowly, between being responsive to locally perceived needs and to providing leadership and initiative. The new role of the rehabilitation therapist and the educator in the area of community development is to help the community examine their own problems and help them realise they have, within themselves, the capacity to meet those needs. The significant role played by the various groups within the rural areas suggests that community involvement in the area of rehabilitation is a feasible proposition.

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3.5 In search of an appropriate infrastructure

CBR may only be viable on a nationwide basis if it can be incorporated into an existing government machinery which already has an operational rural service. Incorporating CBR within the primary health care infrastructure has proved to be a practical proposition in northern Kenya (Arnold, 1986), and in the Talisay area of the Philippines (Valdez, 1984). In the Philippines each primary health care worker began working with three disabled children and once they proved effective in the task, they were allocated ten disabled persons to work along with.

The effective outreach programme in Zimbabwe (Mariga and McConkey, 1987) was based on a partnership with a variety of agencies already working in rural areas: Red Cross, Cheshire Home and the Ministry of Health. An effective infrastructure already existed and was well accepted in rural communities, thereby allowing the new programme to be speedily implemented and effectively integrated with existing community work. The programme therefore utilized and stimulated existing structures. The CBR programme works through established agencies and only moves into an area upon invitation.

The method of facilitating community-based services may therefore vary from one location to another with the innovation being adapted to the respective strengths of each community.

3.6 Recruitment of volunteers from the community

In the Philippines, Valdez (1984) and Periquet (1984) suggest it is possible to find volunteers willing to work for three to four hours per day on CBR activities. The volunteers' major motivation was their increased standing within the community. In areas in the Philippines where it was impractical to introduce CBR through the primary health care structure volunteers were therefore effectively used.

In Zimbabwe (Mariga and McConkey, 1987), Zimcare Trust is working with hundreds of disabled children with a professional staff of no more than a handful. They have therefore demonstrated what can be achieved through vision and creativity in effectively utilizing readily available resources.

In Kenya (Arnold, 1986), the home visitors were school leavers from the community. Their task was to examine the human and material resources which existed in the community and to see how they could be utilized most effectively. The programme used volunteers and they were highly regarded by the families.

In Zambia too, Serpell (1985) notes that the volunteer home visitors were capable and willing, under supervision, to work with disabled persons. He observed, however, that this may be more practical over the short term while the initial enthusiasm is still high and warns that it remains to be tested whether this method of providing rehabilitation can work over longer periods of time. Arnold (1986), in Kenya, acknowledged the need for two or three full-time workers to act as a catalyst to the programme. In some cases therefore the volunteer ethic alone was not enough.

Volunteers did, however, prove to be effective over the 18-month life of the Guyana CBR project. Over 60 persons applied to be accepted on the programme as volunteers. There was therefore an element of competition in being 'selected'. The final 30 participants represented a wide variety of experiences. It was not difficult to recruit home visitors, for half of them their concern for children and their desire to be of service to the community was sufficient motivation to explain their participation. The majority soon became involved in the course and began to regard the project as their own.

There is, however, a danger in fostering the myth that anyone could be effective as a home visitor, an illusion which is perpetuated by a high reliance on the hardware of packages and checklists. The materials are, of course, only as good as

the people using them. The qualities needed to be effective in the role of a home visitor need to be examined.

The Guyana programme undoubtedly benefited from the presence of volunteers from health and education backgrounds, such persons being known and respected within their village communities. However, no professional training could provide the tact, sincerity and devotion which some of the home visitors showed in working with the families. Some of the most effective home visitors were housewives with no more than a few years of schooling. One of the volunteers had four children, two of whom were handicapped. Despite her own problems she worked with four other families with disabled children. What she lacked in formal education she made up in empathy and compassion. Some of the home visitors were remarkably involved in the programme despite the lack of support from the child's family. One of the home visitors worked with the daughter of a security guard. The child was left at home in the care of a blind grandmother. Despite the lack of support the home visitor met the child regularly, and the shy, isolated and withdrawn girl who refused to speak, emerged, through the caring, supportive relationship offered by the home visitor into a normal, lively 5-year old.

An analysis of the independent evaluator's assessments of the Guyana programme revealed no significant correlation between the home visitors' educational background, income and occupation and their effectiveness on the programme. This project worked through two sets of home visitors, one was volunteers from the community and the other was nursery-school teachers who worked on the programme as part of their regular school day. In the nursery sample the key role of a motivated supervisor was evident. In the one school where the head teacher was highly supportive of the project, all the staff were involved in the programme, in the other schools where the administrative support was far weaker the attitude of individual teachers was far more variable.

Only about 6/29 of the nursery teachers were highly involved in the project, with 14/29 who either did not

participate or who showed no more than passive indifference. This illustrates the gulf between the intellectual rationale of the planners and the reality of the situation. On paper the plan looked excellent. Nursery teachers are employed full time; however, the children only attend school in the mornings, leaving the teachers 'free' in the afternoons. The afternoons were given over to the 'planning' necessary for the next day's work. CBR was, however, regarded as a burden to a group of people who felt themselves to be poorly paid. To take on something extra for no remuneration was clearly unrealistic in their eyes. This raises fundamental questions regarding how to incorporate CBR into an existing government infrastructure to expand coverage at an economically viable rate.

There may never be enough money to train all the professionals that are needed; a re-examination of who constitutes the staff is therefore necessary. The CBR literature suggests that volunteers from the community, if effectively trained and supervised, can play a meaningful role in helping disabled children. More imagination is therefore required concerning the recruitment and deployment of volunteers from the community, using limited time commitments, linked on a person-to-person basis and including flexibility of timing of contacts.

The utilization of resources within the community has potentially far-reaching effects. A number of the home visitors in the various projects reported that the CBR experience had impacted on their lives, increasing their own self-confidence, self-respect and feeling of personal significance by realizing they could contribute something of value to others. Moreover as Werner (1976) notes, if the home visitor is taught a respectable range of skills, if they are stimulated to think, to take initiative, they can become agents for change, awakening their fellow villagers to their human potential and ultimately, their human rights. The new model of manpower has far-reaching implications.

To date therefore, the major innovations in CBR have been through either volunteer or primary health care initiatives.

The potential contribution of the most widespread rural service, the education system, has yet to be fully explored.

Indeed the recent ILSMH document, Education for All, (ILSMH, 1990), asserts that, for the most part, the regular school system has denied participation to handicapped children throughout the world. This exclusion results in the handicapped child being deprived of the right to belong and contribute to the community. They offer the reminder that disability should be regarded as a challenge. The challenge is to respect the uniqueness of each individual and see how to facilitate their membership in our schools and the wider society. The special need of the handicapped child is to belong, to be a part rather than apart from the community.

ILSMH do not however belittle that challenge. They recognize that in attempting to work through the most under-utilized of all our community resources, the neighbourhood school, effective planning and preparation are essential. ILSMH cite examples from seven countries to illustrate this point. Based on that experience they raise a number of questions.

Who will take responsibility for overseeing the attempts at integration and monitoring the effectiveness of the exercise? The experience of the Department of Special Education of the Ministry of Education in Zimbabwe in developing integrated education programmes for children with disabilities should be closely examined as a pioneering step in responding to this question.

What criteria will be adopted for judging the effectiveness of the integration experience? The integration of a group of Down's Syndrome children in Spain was regarded as effective in the area of social integration and offered a good foundation on which to build later. Thought therefore needs to be given to assess what 'successful' integration means in practice.

What support will be offered to the regular school in terms of personnel, training and special resources? ILSMH noted that such support was an integral feature of the effective integration ventures in Britain, Sweden and Norway. In particular, consideration needs to be given regarding support for teachers in the context of developing countries where the classroom teacher is often working under difficult conditions. The need for smaller classes in the regular school to accommodate children with special needs was stressed in Spain.

What can be done to prepare the whole staff of the school for integration? The example ILSMH cite from Italy illustrates the dangers when the exercise is based on the skill and initiative of certain individuals rather than being a more broad-based programme.

What can be done to prepare personnel for their role as support teachers or consultants? Innovative programmes such as those adopted in Zimbabwe and Gaza could be examined to respond to this question. A Portage model of home-based education has been introduced to 300 families of mentally handicapped children in Gaza through mobile teams managed by staff from a special school. A similar model has been adopted by Zimcare in Zimbabwe.

What can be done to develop the rich potential of peer tutoring? A decade of experience with child-to-child activities throughout the world has offered a series of simple and practical approaches for nurturing this invaluable resource. More consideration is now needed to see how to continue this process by providing the appropriate training and support to the children and the class teachers within the regular school system. Of all the resources available, the other children in the school, offer the greatest potential for real change in the lives of disabled persons.

What can be done to modify the curriculum within regular schools to make it suitable for children with special needs? The ILSMH example cited from Zimbabwe and our own experience

in Guyana suggest that careful preparation is needed here to ensure the handicapped child is not regarded as a burden to the class teacher and then simply left to dream at the back of the class.

In working through the regular school system how can a more effective partnership be developed between parents and teachers? The need for this working relationship is illustrated by the experience in Zimbabwe where a number of parents of disabled children were sceptical concerning the treatment their child might receive from the other children in the school.

A number of the early experiences with CBR have used either primary health care workers or volunteers as home visitors. These sources alone cannot meet the task. The challenge now lies with educators to see what can be achieved within the regular school system to give handicapped children a sense of belonging. The ILSMH document emphasizes the foundation and preparation that are necessary to make the outreach effective. With such preparation the Guyanese experience with nursery teachers might have been more effective.

3.7 The effect of CBR on children and their families

(i) Need for a broader concept of evaluation

Does CBR work? If so, how does it work? For whom is the approach most effective and how could CBR work better? What are the potential problems in adopting a CBR approach? What type of parents, with what type of children, benefit from which parts of the programme? Part of the reason why such questions are not easy to answer is because of the lack of suitable methods of evaluating 'successful' outcomes. There is a need for developing an appropriate methodology in formulating responses to the above questions.

Evaluation is the process which attempts to determine, as systemically as possible, the relevance, effectiveness and

impact of activities in the light of their objectives. The definition for evaluation can be easily stated; reliable answers are considerably more elusive.

In a number of parental involvement programmes no attempt was made to evaluate the effectiveness of the programme. The programmes are often inadequately designed thereby making evaluation and replication impossible. Early intervention does not have a uniform impact on all participants, some improve, some drop out, some stay the same and some may even be harmed. The variance in results could well depend on economic and social factors, information that is routinely collected but rarely analysed.

There is presently little reliable evidence for predicting which families are likely to benefit from the intervention programme.

The label 'research' has become synonymous with employing the 'scientific method', with technical excellence being the accepted criteria for evaluation. The strong endorsement of conventional methods of evaluation has blocked the search for valid alternatives. The search for methodological purity has sometimes overlooked the substance of the problem to which the methods are applied. Evaluation has become a strait-jacket in measuring performance where, 'the tools have now become our masters'.

There are, however, growing signs that the dominant paradigm is no longer all-persuasive. Assessing the impact of a fixed plan is not necessarily the best use of evaluation, improving the programme is a higher goal and one to which formal quantitative comparisons usually contribute very little.

The adoption of qualitative methods of evaluation is not only because of the limitations of the quantitative approach but because topics for inquiry need to be matched with appropriate forms of evaluation. Too often topics are defined for inquiry in terms of what can be handled by quantitative methods. However, human action and behaviour can only be

understood in terms of how the participants perceive and understand significant events.

Werner's (1987) evaluation of Project Projimo illustrates some of the problems inherent in the evaluation process. Sixty per cent of the clients were judged to have clearly benefited from the programme. However, many of the remaining 40 per cent had also progressed but in more subtle ways. The danger is that evaluation focuses only on what can be readily measured and intangible feelings such as, increased hope, improved relationships with others, and self-satisfaction are overlooked.

Werner (1987) cautions that an evaluation could report an 'improvement', even though the improvement could be tragically small compared to what it could have been. Therefore, to report 'improvement' without indicating how much improvement there was relative to how much there could have been, might be very misleading.

Success cannot be judged solely in terms of the client's performance on some measurable scale. The child's progress needs to be viewed from the context of their particular disability. The value of CBR may reside as much in the opportunity provided for a supportive, caring and befriending relationship as in any developmental gains in the child.

A major obstacle to meaningful evaluation has been the lack of measurement tools for social, affective and interpersonal change. We need to rethink the concept of 'success' and 'failure' and investigate better methods for assessing the quality of life of the child and the family. Priorities have instead often been set in terms of what can be easily measured. The goal of qualitative evaluation is to examine the process of the innovation and not simply focus on the products; the objective is not to predict but to understand.

CBR may have a fixed plan; however, the interpretation by staff and the involvement of clients determines the outcome.

In asking if a play 'works', one must go beyond the script to analyse how the roles are portrayed. The evaluation needs to focus on the 'process' of the innovation rather than simply examining 'results'. It is not enough to ask, 'does CBR work?', one needs an understanding of what happens on the programme.

An analysis of the strengths and weaknesses of the innovation, the quality of the family's experience and the constraints under which the programme operates, needs detailed, holistic descriptions.

(ii) The effect of CBR programmes on the clients and their families

An independent evaluation of the Zimcare Trust programme (Madzima, Matambo and Else, 1985) was based on an examination of the materials, curriculum, training procedures and supervision practices which were adopted. Forty-one children from the programme were randomly selected for the evaluation which was conducted by a series of interviews with parents, care-givers, co-ordinators and local support staff. The children's progress was assessed as: 'outstanding' 7 per cent, 'very good' 32 per cent, 'good' 24 per cent, 'little' 24 per cent and 'almost none' 10 per cent. The conclusion of the independent evaluators was that the co-ordinators of the programme should be congratulated for the vision and creativity which characterized the project.

Positive results were also recorded in Malaysia (Jaekle, 1986), where individual rehabilitation plans were developed for the visually impaired clients. The plans were devised by the field workers recruited from the community in collaboration with the field supervisor. The result was that services for the visually impaired were significantly expanded. The evaluation based on field visits, interviews and reviews of training records, noted considerable practical benefits to the families.

The independent evaluation of Project Projimo (Villegas, 1985), recorded that the majority of clients felt 'improved',

'less dependent' and 'more integrated into society'. In the evaluation of 43 clients, 21 per cent were judged 'not to have improved', 35 per cent saw 'little improvement', whilst 28 per cent were judged to have 'moderately improved' and 18 per cent to have 'markedly improved'.

One hundred and six clients on the Philippines programme were assessed by independent evaluators (B rman and Sisler, 1984). Twelve per cent were judged to have received 'a major benefit from the programme' and in 41 per cent of the cases the improvement was regarded as 'modest'. There was 'little improvement' in 46 per cent of the cases. One conclusion that the researchers came to was the need to match clients with an appropriate rehabilitation plan. Those who are capable of benefiting from services would therefore get more extensive training compared to those who are assessed as only likely to benefit in a moderate way.

By comparison the Zambia (Serpell, 1987) project, illustrates the very variable results characteristic of many CBR projects. Zambia embarked on a very ambitious national campaign to reach all the disabled children of the country. The two-year follow-up revealed inconsistent results, ranging from some highly encouraging successes to other cases where nothing had been done.

In the Guyana programme the Griffiths test (a standardized test of mental development) revealed significant gains for both the children working with the volunteers and the children working with the nursery teachers. Similar progress was evident on the Portage test. Under control, or baseline conditions, the overall gain was 0.67 items per month per subtest. Under treatment conditions, however, the figure rose to 1.95. Six months later, at the follow-up, the figure was 1.02 items per month, per subtest. In terms of completed studies there was no noticeable difference in the results between the two groups of children. However, when the children are included where the home visitor stopped working with the family within the first three months of the programme, the results of the volunteer group were consistently better than

the nursery teacher sample. Twelve of the nursery teachers did not continue the CBR programme as compared with only two of the volunteers.

All of the mothers working with the volunteers and 12/18 of the mothers working with the nursery teachers, noted important changes in their children who were regarded as happier, more mobile, more motivated and better behaved, changes which were confirmed by other members of the family.

It should be emphasized that in the great majority of cases the various CBR projects were reaching children who, with the exception of a few persons, had previously received no help whatsoever for their disability. Moreover, few of them would be likely to receive any help in the future if CBR was not offered.

When asked to evaluate the programmes, a number of mothers emphasized the emotional and psychological support they had received from the home visitors. The general goals of supporting, caring and befriending the parents identified as crucial variables in the Portage programme have also been key considerations in the CBR programmes. Simply visiting parents regularly and offering genuine positive advice had a significant effect on the way the mother treated the child. Parents apparently drew strength from the support offered by the home visitor. This highlights the limitations of simply focusing on a structured teaching programme and contradicts the advice not to get drawn into a counselling role. The value of the programme may lie as much in the relationship between service agents and family members as in the specifics of the practical intervention which they propose.

All of the mothers working with the volunteers and half of the mothers working with the nursery teachers in the Guyana programme saw important changes in themselves as a result of the project, feeling more relaxed, less depressed, happier, more confident and more aware of the child's potential. The changes were, however, far more characteristic of the mothers working with the volunteers than the mothers working with the

teachers. These results from the mothers were confirmed by the home visitors who commented on the mother's increased interest and their enhanced knowledge concerning how to help the child.

The concern of many of the mothers changed from questions about causation to a desire for help in specific areas. They felt more aware of both the child's abilities and their limitations. The goals of the parents became more long term and in many cases more realistic. Aspirations changed from a desire for the child to be 'normal' to hopes for progress in specific problem-areas. Vague goals 'lead a happy life' became more definite, such as 'training in feeding'. The changes were characteristic of both groups, but the more significant gains were by the mothers working with the volunteers.

The mothers' attitude towards the child changed in a number of cases. Before the programme began 23/26 of the mothers working with volunteers spoke of being sad, depressed and worried concerning the child's future. Only 1/26 of them felt highly confident in dealing with the child. Following the project 15/20 of the mothers had gained that confidence and 9/20 anticipated a bright future. The mothers therefore reported changing over the course of the study in a positive direction. These observations were confirmed by independent evaluators.

The programme had a noticeable effect on the mothers' attitudes towards the way other family members and the wider community could assist with the child. Initially, such thoughts were vague and general, however, at the end of the programme the ideas were far more specific. Once again, however, the gains were more noticeable for the mothers working with the volunteers. They changed their conception of the attitudes held in the community towards persons with disabilities. Initially the mothers regarded the community as generally unsympathetic and unsupportive but by the end of the programme almost half of them felt that the community was helpful towards disabled persons. The number of mothers who felt free to discuss their child with neighbours doubled over

the course of the project. Moreover, the parents were encouraged to seek out contact with other parents of disabled children. Sixty per cent found such meetings of great benefit.

The great majority of mothers went to some length to explain how valuable the programme had been to them. They appreciated the regularity of the visits, the practical advice given concerning how to stimulate the child, the information on access to institutional-based services, the care and interest shown by the home visitor and the fact that someone else valued their child.

The only apparent significant relationship between the child's progress and selected variables was the measure of parental involvement. It is not surprising therefore that the more noticeable gains came from the mothers working with volunteers as this group featured far more parental and community involvement than the nursery group.

3.8 The establishment of links with institutional-based services

Before the Guyana programme began only six of the children had been exposed to specialized help for disabled children, the remainder having received no professional help beyond routine medical examinations at the local clinic. In many cases the parents had been totally isolated, with their disabled child receiving no help from any quarter. The great majority were unreached by any service. Because of transportation problems none of the children was attending institutional-based facilities when the project began. By the end of the project 11 children had been referred to such centres. Four of these children were accepted in the regular school as a result of the intervention of the home visitor and the programme co-ordinators. However, these children illustrated the need for an effective partnership between various agencies. In this case the children remained at the back of the class and little was done to begin to meet their specific needs. Their case illustrated the need for more effective early preparation and co-operation with the ordinary school. It is all too easy to

see the placement of a handicapped child into the ordinary school as the major goal and to fail to appreciate that this is only the beginning of the process. A better preparation was needed to influence attitudes within the school and to mobilize support from the teachers and the other children within the school. The need for ongoing support of the teachers also needs to be recognized. Despite these real limitations a beginning was made in increasing community awareness and promoting a measure of social rehabilitation. A foundation therefore existed on which to develop.

The process of referral was more effective in the cases where operations were needed, making institutional-based services comprehensible and accessible to the mothers. CBR has been effective in many instances in introducing a number of clients to more specialized facilities available in the capital. However, the access to the special centres has often proved temporary and the integration into the regular school has frequently appeared to be fragile. An intervening stage between institutional-based services and CBR may therefore be necessary to span the gap between these two approaches.

It has become fashionable to criticize the concept of institutional-based provision of services. However, it is more realistic to regard the two forms of service provision as complementary, the strengths of one counteracting the weaknesses of the other. Institutional-based provision is often dismissed for utilizing a disproportionate share of the resources for only a privileged few. The very real strengths of the approach are often overlooked in the emotional debate. Professionals possess specialist knowledge and confidence in their abilities which is infectious. Institutions nurture an accumulation of experience, provide opportunities for in-service training, the possibilities of breakthroughs and much valued relief of family burdens.

The antithesis of CBR and institutional-based services is artificial. For CBR to be effective a strong partnership needs to be established with rehabilitation therapists and special educators to support the community workers. Miles has

demonstrated the value of community-based rehabilitation centres with mid-level trained workers, run by the community, using local materials and offering a valuable training base for parents and professionals from other areas. Such a centre is perhaps essential to make the link between the community workers and the professional services and between the health and education components. The sustainability and the technical quality of the programme may, in large part, depend on this intermediate link. It is perhaps in developing countries, where services are in the process of being developed, that a new pattern of services can be pioneered. Therapists, educators and planners in developing countries have the challenge of reconciling the debate between the various forms of service provision and offering a more realistic model to meet the pressing needs.

4. LIMITATIONS OF CBR

4.1 Need for an independent evaluation of the concept of CBR

The limitations of the institutionally based model of rehabilitation can be easily appreciated; however, the danger is that an innovation is justified purely on intuitive rather than empirical grounds. There is a tendency for fashions to develop which become slogans and which are adopted before their impact is fully evaluated. The reason for their popularity can lie more with their energetic promotion rather than any inherent benefits of the programme.

The World Health Organization pilot tested CBR in nine countries and convened a meeting in Sri Lanka to evaluate the results. They concluded emphatically that 'CBR is an appropriate, feasible and economically viable approach to provide the most essential rehabilitation in developing countries' (WHO, 1982). Some of this data has been questioned by Miles (1985) and O'Toole (1987).

Nevertheless, the approach has been widely accepted by international organizations to such an extent that by 1984 CBR was adopted and co-sponsored by WHO, UNICEF, ILO, UNESCO and UNHCR as part of their contribution towards the Decade of the Disabled. CBR has also been supported by non-governmental organizations throughout the world, including: Rehabilitation International, World Rehabilitation Fund, Red Cross, SIDA and NORAD.

Momm and Konig (1989) observe that rarely in the history of services for disabled persons has an approach attracted so much unqualified support as has CBR. However, in their review

of the International Labour Organisation experience with CBR over the past decade they concluded that the International Labour Organisation has had no experience with a really effective CBR programme which could demonstrate its ability to carry on solely with local and national resources once outside support ceases. They argue that presenting CBR as a simple, cheap alternative overlooks the significant needs for resources, supervision and follow-up which are essential to gain the support of the local community and the ultimate target group, the disabled persons themselves. Their conclusion is that the main outcome of the International Labour Organisation experience with CBR has been an increased awareness of the difficulties accompanying the implementation of the process.

Miles, who has presented one of the most detailed critiques of the approach to date, is concerned that 'a number of dedicated and hard-working volunteers are being persuaded to work in a scheme which has a number of fundamental flaws' (Miles, 1985).

He stresses the need for independent evaluations of CBR. A beginning has been made in this respect by the evaluations of Madzima, Matambo and Else (1985) in Zimbabwe, Berman and Sisler (1984) in the Philippines, Jaffar (1990) in Pakistan, AMREF (1987) in Kenya, and O'Toole (1990) in Guyana.

There is a danger that CBR has been presented as a panacea, one approach equally relevant to societies as different as Saint Lucia and Pakistan. Institutional-based services alone cannot meet the need of disabled persons whether in the West or the developing world. An evaluation of the concept of CBR is therefore necessary because of the very real potential of the approach.

There is a need, however, to move away from uniformity myths and investigate for whom such an approach is meaningful: which children, which families, what types of disabilities, and to see which home visitors are effective. A detailed evaluation is therefore needed to determine whether CBR can

meet the needs of disabled persons in a developing country, or indeed in a developed country, in an effective and inexpensive manner. More knowledge is also needed concerning the implementation process and the dynamics of the innovation to help in the formulation of more meaningful programmes in the future.

4.2 Is CBR a realistic way of closing the gap between need and available provision?

The real test for CBR is yet to come. Can CBR expand beyond a relatively small-scale, home-based teaching model into a nationwide, community care programme? To achieve total coverage is undoubtedly difficult. The Zimcare experience illustrates the need to form a partnership with a variety of different agencies as there is a danger of only certain types of problems coming to the programme's attention through individual agencies.

It remains to be seen how many persons could be helped with the CBR approach. Whilst the Guyana project revealed that it was impractical for the home visitors, whether volunteers or nursery teachers, to work with more than one or two children, other programmes, such as in the Philippines (Valdez, 1984) found volunteers who were each capable of working with ten or more disabled clients. However, even if a volunteer works with ten clients, still the logistics of organizing and supervising such a widely dispersed programme are daunting.

Innovations, by nature, are artefacts creating changes which would not normally occur and which are artificially kept alive by special energies, funds and expertise. The challenge is to see what happens when the protected subculture disappears and the temporary system is absorbed into the government system, using local officials not so committed to the project.

Many of the projects demanded considerable involvement from the co-ordinators. Part of the expansion therefore could

be to pilot the programme in situations more comparable to normal conditions integrating the CBR services into the remit of agencies which are already working in these regions.

Attempts should also be made to investigate the skills necessary on the part of the co-ordinator to manage such a project. Research in Britain has shown how demanding the role of the home visitor is. Even qualified health visitors have expressed feelings of inadequacy concerning visiting the homes of disabled children. In our enthusiasm to embrace the philosophy of home-based care we may fail to appreciate the very real demands such an approach makes on the key players.

4.3 Are the expectations made of the home visitors realistic?

CBR requires home visitors to be flexible, innovative and imaginative; however, it could be argued that most formal education in developing countries favours memorizing and imitation not creativity.

A number of projects have expressed reservations concerning the viability of home visitors. In India it was felt that while Anganwadi workers may be effective in identifying persons with disabilities they could not be expected to provide the necessary rehabilitation services.

Serpell (1986) in Zambia recorded the low enthusiasm of some home visitors and felt that financial incentives were necessary to stimulate higher motivation. Jaffar (1990) was very critical of the work of home visitors in Pakistan. He argued that none of the home visitors carried out even half of the activities they were supposed to do. As a result of limited training and a lack of any professional identity the families tended to perceive the home visitor as one of them rather than as a trained person who could help disabled persons.

However, the problem of limited training is a challenge to which CBR can respond. A number of questions in this area

need to be examined. What is the miminum level of training that needs to be given to home visitors to enable them to offer safe, effective assistance to disabled persons and their families? What technical skills do home visitors need? Should the home visitors be specialists or generalists? Should CBR develop a 'career path' or is there a danger in professionalizing the approach and thereby losing touch with the community? What sort of people should be identified as home visitors? Younger persons may have more energy and might learn faster; however, they are also more mobile and ambitious. Should some informal system of ability testing be adopted to select 'appropriate' candidates? Who should carry out the selection process? In training the home visitors how can problem-solving skills be taught? How can rehabilitation activities be incorporated into other aspects of rural development? How can the home visitor be examined to see if they have acquired the necessary competence? How can under and over training be balanced? If the training is too brief the home visitor can feel inadequate to the task and yet if the training is too sophisticated the home visitor may feel frustrated by the role they are asked to play. Indeed, the levels of training may need to be upgraded as the community develop higher expectations of what they expect the home visitor to do.

The difficulty of supervising a widely diffused network of individual CBR programmes can result in the services being more nominal than substantial. Adequate training of the home visitor is obviously a crucial first step. However, they then need sufficient support and supervision to meet the demands, resistance, suspicion and reservations of the community. Whilst supervision is acknowledged in practice it is often fragmented, sporadic and insufficient. The objectives of supervision need to be more specific and the supervisors need to be trained in relevant techniques and then supported themselves.

4.4 For whom is CBR a relevant approach?

For some parents poverty, overcrowding and ingrained negative attitudes make involvement in such programmes impractical. In a number of cases there is simply no one available in the home through which to introduce such a programme. In some societies the homes may not be open to outsiders. The emotional and psychological problems in other homes may mean that the home may not be an appropriate learning environment.

On the other hand there were parents in the various programmes from equally disadvantaged backgrounds who were able to rise above their circumstances and play major roles in the project. We perhaps need to be reminded that families with disabled children were just ordinary families before the arrival of their child. The great range of parental responses as seen in the various programmes should not, therefore, be surprising.

An essential element of CBR is to change attitudes in the community towards disabled persons. There may, however, be a conflict between traditional and more progressive attitudes. Some disabled persons accept their disability as their fate. If disability is regarded as a 'curse' it will be difficult to introduce a home-based model of rehabilitation. In Zambia (Serpell, 1986) the community was passive, the government was expected to provide all the necessary materials. At least in introducing CBR projects one needs to be aware of the great range of socio-economic conditions and should be wary of proposing 'one plan'.

The available literature offers some suggestions concerning which children may profit from the CBR approach. Whilst Mariga and McConkey (1987) note the positive results recorded by the younger children on the Zimcare project they also observe the practical problems of overcoming the reticence of parents in accepting that their pre-school child was in fact disabled in some way. Berman and Sisler (1984) also note that pre-school blind children are likely to have special problems which a home visitor is unlikely to be

competent to deal with. On the other hand older blind persons were already independent and were often already 'adapted' to their disability.

Hindley-Smith (1981) found that persons who had recently become disabled were more likely to benefit from CBR. This was confirmed by Villegas (1985), especially in the cases where the disability was as a result of an accident.

The Guyana programme noted improvement in the physically handicapped children in particular. As a group they benefited from referral to specialist facilities. The mentally handicapped children were more evenly divided between the various categories of progress suggesting that the nature of the child's handicap may impose limits on what is possible. Whilst those limits should be constantly tested, one needs to present a realistic picture to parents concerning the possibilities. Some children, noticeably those with severe hearing impairments, may need more specialized services than those offered by the CBR approach. The sensory problems were often resistant to training at this level. Further research is therefore needed to see what could be achieved in a programme under the regular supervision of a speech or hearing therapist. In considering which clients are most suitable for a CBR approach it is worth remembering that in the absence of the CBR projects few of the disabled children would have received any assistance.

The philosophy underlying parental involvement is not alien to the context of developing countries; however, real, practical constraints need to be appreciated. Some parents may enthusiastically embrace the teaching role, for others the role is too demanding. More research is needed concerning the precise variables within the child, family and community which contribute to effective programmes. The one certain conclusion is that no easy stereotypes prevail concerning those for whom CBR is relevant.

4.5 Through what infrastructure can CBR be introduced?

There has been great disparity in the interpretation of what constitutes a CBR service. On the one hand CBR has been presented as an entirely non-institutional service, working through members of the family and the wider community. On the other hand it is envisaged as an outreach or extension of conventional services, thereby bringing professional services to a larger number of disabled persons and referring those in need to the necessary specialized services. The second conception sees CBR as complementary to institutional provision and indeed depends on institutional-based supervision and technical support.

Moreover, whilst the theory of CBR presents an interdisciplinary framework, in practice it has often been assumed that CBR will operate within the health system. The programme co-ordinators are frequently envisaged coming from a primary health care background, responsible to a health committee. However, there are a number of problems in attempting to graft the CBR system on to primary health care.

Health is often given a relatively low priority in rural villages, behind more pressing needs such as improved education, better markets and water supply. Improved medical services are not always therefore given a high priority in rural villages. If health is given a low priority, care for the disabled will be far lower.

In promoting CBR there has been an assumption that governments are genuinely committed to such developments. This has not, however, always been forthcoming in the area of primary health care. It has been argued by David Werner that 'the greatest obstacle to bringing effective health care to the masses are the doctors and the politicians' (Werner, 1978). Services are still regarded in a paternalistic manner; health is something to be delivered to the masses. The reaction to the introduction of auxiliaries has been a mixture of contempt and alarm. Auxiliaries have been regarded as competitors rather than partners in meeting the health needs.

Momm and Konig (1989) offer a timely reminder of the popular movement in the 1960s and 1970s in the West towards deinstitutionalization in the area of mental health. The movement was largely conceived in economic terms as a way of saving on tax dollars. The search for a cheap alternative to rehabilitation institutions could therefore become the major guide to policy recommendation in the area of disability internationally.

If the political and professional support has not been forthcoming with primary health care there is less likelihood it will be given for CBR. Miles (1985a) can already hear the 'anguished reaction of the rehabilitation professionals who see their trade secrets being hawked in the market place'.

Primary health care has been regarded in some quarters as losing momentum; it has become stigmatized as the poor people's medical circuit. Primary health care is promoted in words while urban, highly technical care is supported in deeds. The dual standards are not lost on villagers who simply ignore the services. The local services have often been by-passed with the villagers approaching the more distant facilities in the cities. Villagers now often have urban-type expectations.

A number of effective primary health care programmes have been either part of an international research project with significant manpower and financial investments or based on the charisma of key personnel. The disillusionment of pilot projects which remain as pilot projects is widespread. Few pilot programmes have effectively spread beyond the original setting. Questions have been asked whether local programmes can work on a larger scale. The prognosis for innovations is often poor once responsibility is transferred from the pioneers to local government administrators who approach the task with limited ability and enthusiasm.

The primary health care system therefore has a number of limitations. There are, however, added problems in attempting to graft CBR on to the primary health care infrastructure.

Administrators list the many diverse tasks primary health care workers are expected to perform and then suggest that rehabilitation should be an added responsibility. However, it has been estimated that 25 per cent of the health workers' time would be spent on rehabilitation.

Attempting to superimpose a rehabilitation model on a service system which is already overburdened may be unrealistic.

The practical problems of working with poorly educated persons should be noted. As a result of the limited training and the lack of any professional identity families may tend to regard the workers as one of them rather than as someone qualified to work with disabled persons.

By contrast, the Portage system in the West uses home teachers with extensive professional experience.

To the extent to which CBR fails to solve the problem of limited training to persons with little or no previous experience, CBR runs the risk of providing only superficial services and allowing mistakes in the application of poorly understood techniques to go uncorrected for long periods.

Despite such practical problems volunteers are often envisaged as the home teachers. The volunteer ethic has, however, been questioned in a number of countries where the 'volunteers' demanded payment and the co-ordinators felt it was a crucial need.

WHO have advocated primary health care as the infrastructure through which to introduce CBR. In some cases that may be realistic. In Mexico the community health workers were young women from the community who had earned the respect and confidence of the villagers (Hindley-Smith, 1981). In northern Kenya the only mechanism through which to establish rehabilitation was the health system (Arnold, 1986). The village health workers were already working closely with the families in their homes and were the key moulders of attitudes

in rural areas. In these cases the manpower existed and simply needed additional training and orientation rather than major capital outlays.

Whilst there is undoubtedly a key role that volunteers can play in this area, inspired leadership and the enthusiasm of volunteers are not enough. Volunteers may or may not do the job, they could drop out at any time. The turnover of manpower could be high giving problems of continuity with the constant training of new recruits. Whilst the volunteers are effective in providing a form of social, psychological support, they are obviously not equipped to handle the more specialized needs of the children.

In the Guyana project attempting to work through the nursery school system proved to be a demanding exercise with only a minority of the teachers becoming fully involved in the programme. There may well be a significant difference, however, between attempting to 'add on' rehabilitation tasks to professional roles which are already clearly established and incorporating the responsibilities into job specifications from the inception. In Guyana for example an effective CBR module has successfully been included in the training of physiotherapist assistants. It is significantly more demanding to incorporate the responsibility into professional roles that have been clearly defined for many years.

Investigating creative ways of expanding the contribution to be made by volunteers and incorporating CBR into the remit of workers already involved in service projects are crucial to closing the gap between the need and the available provision. Significant efforts have been made to incorporate CBR into the primary health care system, a similar effort is now needed to explore the potential contribution that could be played by the ordinary class teacher. Research is needed concerning how to prepare teachers for this role, what training is needed and what support is required to make this a viable method of introducing CBR into the community.

Imaginative and creative investigation of the available resources in the community is therefore a vital first step in the planning of the services. It should be remembered that CBR is not a package of services but a philosophy of care which inevitably embraces many forms of services. Moreover, it is only when an effective partnership is established between the various sectors, particularly health and education, that significant progress can be made.

A clear government policy is needed concerning who does what, when and with a clear commitment of resources and materials and dissemination of good practice. A minister should be designated with the specific responsibility for disability. Thought needs to be given regarding how to move from effective small-scale projects to large-scale innovations and to investigate how to make the approach work on a large scale with local government officials of average ability and limited enthusiasm. CBR needs to be fully implemented into a national policy with a recognized willingness to adapt rehabilitation programmes to CBR initiatives. The available research suggests CBR can play a significant contribution. Politicians, administrators and professionals now need to consider the infrastructure and training needs which are necessary to fulfil the potential.

The reality, however, has been a very limited commitment on the part of governments in establishing national CBR services. Grass-root workers have generally been expected to cope on their own without external help. No government has considered obtaining the necessary resources for CBR by closing down urban rehabilitation facilities. In most instances CBR has been regarded as an additional programme requiring an expansion of existing social service budgets. In working through an existing infrastructure there may be a danger of deteriorating into a minor facet of an existing service provision to which no particular priority is attached. The Early Stimulation Programme in Jamaica (Thorburn, 1983) began with the hope of becoming part of the National Health System. However, a decade later, with no government support, it has suffered staff attrition.

4.6 Constraints of working with family members

The pendulum has swung from the 1950s when one could have overlooked the fact that parents existed, to the 1980s where parents are lauded with the title of the 'only true educators'. The crucial role of the parents is now enshrined in legislation in Britain, where the court report states, 'we have found no better way to raise a child than reinforce the ability of his parents to do so', and in the United States, where PL 94-142 extends the right and the duty of parents to assume the role of education decision-makers. Parents who were earlier dismissed as part of the problem are now regarded as part of the solution.

The rationale for parental involvement is, however, based on federal mandates, legislation and common sense rather than empirical data. Evidence for the effectiveness of such programmes is limited, often no reference to evaluation is made at all. A number of assumptions concerning the relevance of the concept of parental involvement in the context of developing countries need to be examined.

In the Independent Evaluation of the Family Support Service Programme in Kenya (AMREF, 1987), the difficulty of involving parents was observed. Following a period of initial enthusiasm the parents were often not present when the home visitor went to the house. The parents were not consulted regarding what was done between visits by the home visitor as the expectations of the family were so limited.

(i) Is the concept of parental involvement culturally appropriate in the context of a developing country?

Is the idea of the mother spending X minutes per day teaching the child part of their culture? There may be a danger of a mass export of Western packages to developing countries, adapting the materials on simplistic levels, rather than questioning what the parent is actually being asked to do. Parent involvement programmes may create the problem of forcing children into moulds and pressuring parents to behave

in ways which may be inappropriate for their culture. Parental involvement reflects Western concepts of education and child rearing. Programmes such as the Portage project are set in an American culture and demand special equipment and established routines. Families in developing countries often do not have such a routine controlled life-style. It therefore needs to be examined whether the concepts of education and child rearing which characterize parental involvement projects are meaningful to a population with a very different cultural background.

(ii) Is the role practical?

Overwork, poverty, severe social tensions and sheer exhaustion make parental involvement a difficult proposition in developing countries. Amidst poverty the scarcest resource is time which is devoted to survival. In such societies there may be little or no surplus energy or compassion to spare for the weaker members of society.

Severe practical limitations also exist in the West where such pressing concerns may well threaten the centrality of the child in the parents' lives. In such cases the handicapped child's progress may be the least of the parents' worries. The difficulty of attracting poorer parents to early stimulation programmes has been acknowledged in the West.

The parents most in need may have neither the resources nor the psychological energy necessary to participate in an intervention project, for them only fundamental material improvement may be relevant. It may therefore be unrealistic to assume that it will always be possible for parents to adopt a teaching role with their children; moreover, there may be a risk of imposing both practical and emotional burdens on the families by advocating such a role.

(iii) Do parents welcome the role?

Professionals may be guilty of having adopted a stereotyped model of parents who see their handicapped children as special

responsibilities, and who are willing and eager to offer individual teaching and play sessions to the child. The assumption is that parents would welcome higher involvement in the educational process. The reality, however, may be very different. Assumptions behind parent programmes may be based more on what professionals think parents ought to be rather than on a universally held parental preference for involvement.

A second assumption is that parents would find the work rewarding. Parents often sought relief from their children rather than greater involvement. The question of what happens when the parents are too old to help also needs to be considered. In other families there may be little interest in the child, and in such situations the child may need protection from the family rather than greater integration.

In promoting parental involvement the effects of the handicapped child on the family may be underestimated. An extensive literature exists to suggest 'a handicapped child means a handicapped family'. The characteristic responses of deep emotional upset, extreme isolation, disbelief, denial, grief and depression have been widely documented.

(iv) Is there a danger of an 'educational effect'?

A problem exists whereby the child's performance on a test can become an index of the mother's effectiveness as a parent. The very scheme which was designed to help the parents could undermine the parents' confidence in their own ability to meet the child's needs. A long-term dyadic relationship with a professional could create a sense of dependency by the parents. The goal of an effective home link should, however, be to support and develop parents' skills and to render the professional redundant rather than to make them an increasingly vital contributor to the family's successful development.

Intervention programmes may become too highly child-focused and overlook the wider needs of the family as a whole. Some parental involvement programmes, such as the

Portage programme, have advised home visitors not to get drawn into social, emotional or marital problems, as their expertise is in 'teaching, not social work, counselling or psychology'. However, for the disabled child to function effectively in a well integrated family unit, the needs of the family have to be systematically addressed.

The family has far wider needs than those of the handicapped child alone. Marital and psychological problems are not uncommon. The evaluation of the Zimcare project (Madzima, Matambo and Else, 1985) observed that much of the home visitor's time was spent on matters other than rehabilitation, i.e. counselling of family members and assisting the family economically. Parents repeatedly stress the need for contact with sensitive persons willing to listen.

(v) Does the task of teaching adversely affect the mother's unique role?

Encouraging a mother to behave like a teacher may destroy the very contribution which is most important for her to make and could add stress to a parent-child relationship which is already fragile. Mothers are being pressured into adopting perceptions, expectations and behaviours which may be psychologically damaging to themselves.

Some of the gains from parental involvement projects may be illusory resulting in the parents feeling more in control of their own destiny than is realistic, thereby creating false perceptions and unrealistic expectations. If progress is not forthcoming they either reject the programme or devalue their own attempts. Either way a painful adjustment must result. Parents may begin to feel the lack of progress by the child is their own responsibility.

An added problem in parent involvement projects is the danger of the programme pushing the parents further apart. The father's role in the life of his handicapped child is often limited. By concentrating on the mother-child unit to the exclusion of other family members, the intervention may only

serve to increase the father's isolation and accentuate the differentiation between parents regarding their respective roles.

4.7 Difficulties in involving the community

The community is given a pivotal role in the CBR approach:

> the community must realize that the lives of its disabled members must be improved and that the community itself has the capacity to do it ... the active participation of the community is the key to the success of CBR (Mendis and Nelson, 1983).

However, the concept of a community is often vaguely defined as 'a group of persons living in a certain area'. There may be a danger that the approach has been conceived in light of an ideal village concept, as Momm and Konig (1989) note. Such a village would be characterized with a high sense of community spirit, harmonious relations between individuals and a desire to help one another and take decisions jointly. CBR may, however, gain more credibility if it is based on a less optimistic scenario rather than on a constructed ideal. Momm and Konig (1989) therefore caution concerning the diversity of conditions that need to be satisfied which call for different approaches and solutions.

The social, cultural and economic context within which CBR is to be introduced needs to be considered very carefully. The rural village has become the main focus of CBR planners. However, the vast number of disabled persons live in scattered and rural isolation and in marginalized urban areas and therefore remain, in practice, outside the reach of CBR services. One needs to question whether a deeper understanding of community as entailing a common perception of collective needs and a joint responsibility for decisions is relevant in developing countries. To mobilize previously uninvolved populations with no tradition of community participation and with no mechanism for community involvement is a daunting prospect.

Official mythologies of community participation portray communities as harmonious entities. In reality they are often divided, stratified societies. The conglomeration of castes, factions and classes even within a small village prevent the formation of a concept of community. There is a danger in being unrealistic concerning the extent to which care is shared within the family and regarding the potential support available in the community. In practice, for community we should read family and for family we should read mothers.

In the West disabled persons have been stereotyped as being dependent, isolated, depressed and emotionally unstable. Such negative feelings are amplified in developing countries where the overwhelming impression, from the published literature, of the attitudes towards the disabled is very negative.

Disability is explained in terms of witchcraft, or as a curse from the gods. In a number of areas teaching handicapped persons is forbidden and only brings shame on the family. The attitudes of the more educated persons in these samples were often even more negative than the uneducated persons. These attitudes are a reflection of the austerity of daily life in developing countries. When one considers such attitudes it is perhaps not surprising that community involvement in rehabilitation projects is often absent in such areas.

Community participation has become a new catchword. The challenging reality of translating such laudable principles into action is often not appreciated.

5. RECOMMENDATIONS

5.1 Methods of introducing the innovation

Much of the literature evaluating innovation in the areas of health, education and rehabilitation in developing countries is pessimistic in tone. In spite of large-scale investments, few projects have been effective and most remain as giant pilot projects characterized by poor planning, grandiose objectives, bureaucratic entanglements and a fundamental lack of appreciation of the process of innovation itself. A major reason for the lack of effectiveness may lie less with the nature of the innovation package than the method of introduction.

CBR has often been based on a model in which parents are regarded as waiting and eager for new ideas, they only need to be properly 'informed' and they will change their behaviour. There is an underlying assumption that parents will be receptive to innovation. The recipients only play a passive role in the process. Such approaches are generally regarded as being managed and executed by outside, not local, agencies thereby extinguishing local support and initiative.

More effective models of innovation have, however, recognized the limitations of relying on rational persuasion or administrative legislation. The goal should be to influence people, their perceptions, attitudes and behaviour. The focus therefore needs to be on persons as the point of entry, rather than on goals and structures of the organization. It is people who design, accept and implement changes.

5.2 Ingredients that can help establish a firm foundation for such programmes

The programmes in Zimbabwe (Mariga and McConkey, 1987), Guyana (O'Toole, 1990), the Philippines (Valdez, 1984) and Mexico (Werner, 1987) were facilitated by co-ordinators with a good understanding of local conditions which was earned over a period of several years. The projects were not managed by short-term consultants from overseas.

In the same programmes the involvement of local opinion leaders such as parent groups, local politicians and ministry officials were secured before beginning the project. This preparation along with articles and announcements in the media helped give the participants the feeling they were working on a real, urgent problem.

The involvement of the key rehabilitation professionals at the planning stage often helped to offset some of the potential criticisms of the innovation as the projects were perceived as joint ventures rather than the idea of one person.

Each of the above projects was introduced as an experiment, not as a panacea. They were not presented as revolutionary or controversial, but as questioning the potential of the approach; as such they did not arouse opposition.

The Guyana programme was deliberately planned on a small scale despite the invitations from a number of sources to increase the coverage into other regions. The small scale, however, allowed quick and efficient communication, co-ordination and decision-making. The programme was regarded as a demonstration project to see what could be achieved with relatively modest investments; however, at the same time, thought was given to see how the gains of the programme could be maintained.

The idea for the programme came from the writer. However, the concept was soon shared and became a joint enterprise on

the part of a number of persons in the education and health fields. The programme was deliberately planned to have a number of principal participants.

The co-ordinators of the Guyana programme felt that to have a lasting impact the innovation needed good relations with government at the highest levels. To achieve this the programme had to work within government structures and not seek to create new ones.

A strong foundation for the various programmes was therefore established at the outset, based on: clear commitment by the co-ordinators, keen interest of the home visitors, adequate financial support both locally and overseas, administrative support within the various ministries and the assistance of rehabilitation professionals and parent groups.

It should be noted, moreover, that these programmes were conducted in areas experiencing fairly severe socio-economic constraints, including devaluations, blackouts, transportation problems and petrol shortages.

5.3 Need for ongoing training

As significant expansion of institutional-based services is impractical, it is left to CBR to see if the new model can effectively meet the challenge.

The need for ongoing training and supervision is essential in ensuring the quality of the service offered and in maintaining the enthusiasm and involvement of the home visitors.

Detailed attention to training was a characteristic of some of the effective early intervention programmes. In Malaysia (Jaekle, 1986) and the Philippines (Berman and Sisler, 1984) the home visitors had an intensive six-week training programme before commencing work with the family. Throughout the programme the home visitors received ongoing

training. Two-day study sessions and case-review conferences were held twice per month and provided a vital in-service training mechanism. Each of the clients was monitored in a one-year follow-up exercise. Visits to the home were made on the basis of the client's needs and grew less frequent once the client demonstrated that the support was no longer necessary. The support of the home visitor was gradually phased out with a formal case closure exercise.

The independent evaluators in each of these programmes were highly impressed by the commitment shown by the co-ordinators and their ability to instil that same motivation in those they worked with.

In Project Projimo an effective informal support system is clearly evident. Skills are acquired through an informal training process. The key to the success of the programme appears to be the highly dedicated and talented staff who are prepared to work for modest remuneration but with considerable community backing.

In Kenya (Arnold, 1986) the co-ordinators visited the home visitors on a regular fortnightly basis. In the more remote areas visits were made for three or four days every two months. It was felt that such concentrated on-the-job training was required to develop the necessary knowledge, experience and enthusiasm. Such training was thought to be essential for approximately 18 months following which a less intensive form of supervision would be sufficient.

One of the limitations recorded in the Zambia (Serpell, 1987) programme was that the home visitors felt they needed more supervision from persons with higher expertise in the area. The modest results were attributable, in part, to the lack of ongoing training following the initial two-week training in the assessment and registration phases.

The '3D' programme in Jamaica (Thorburn, 1990) also featured several weeks of intensive training before the home visitors began work with the families.

In the final analysis a programme succeeds or fails as a result of the calibre of the staff available. The qualities needed to become effective home visitors and the precise training and supervision requirements need to be investigated further.

The effective programmes included extensive and prolonged follow-up activities, reflecting the way in which these projects do not underestimate the magnitude of the task they face. Throughout such programmes ongoing workshops were held for the home visitors.

5.4 The key contribution of the home visitor

Influencing parents' attitudes and expectations and nurturing the belief that the child is capable of learning and worth helping may be the crucial contribution the home visitor can play. A sensitive analysis of the role the home visitor plays in the home would have important implications concerning the focus of the project. If attitudinal change proves to be the key variable this would significantly influence the type of training programme offered to the home visitor.

There is persuasive evidence that suggests greater progress when home visitors visit less regularly than every week. The parents who are visited less regularly retain the role of protagonists, are less dependent on the home visitor and invest more effort in helping the child. Attempts need to be made to see if this research evidence would be relevant in the context of a developing country.

5.5 The role of the professionals

The key to improved services depends on a more innovative approach to manpower utilization and preparation. The challenge for the professional becomes learning how to give away their skills; that, however, may prove to be one of the most demanding tasks for professionals to learn. The speed and scale of change in the field of teaching and rehabilitation has been so rapid that it is hardly surprising that many, if

not all, staff are unqualified and ill-equipped to meet the challenge of the coming decade. A wider form of training is therefore necessary to include adult learning, consultancy skills and methods of introducing innovations.

The new role for the therapist and the educator is to nurture the abilities within the child, home and community and to facilitate and support the family and the volunteer. Training needs to focus on the rationale for this co-operation and help overcome the unrealistic expectations parents and educators often have for each other.

The role of the therapist and educator is to inspire and advise, not to make unilateral decisions. The goal is to show villagers how they can cope more adequately with their own problems. A major goal for the therapist and educator is therefore as promoters of community development. Their task is not to supervise and judge the home visitor but to accompany them in their efforts.

The key role of the co-ordinators in the Projimo project was apparent in the supportive model of supervision that was adopted. Various professionals visited the clients in their homes along with the home visitor. The therapists' role was supportive, giving suggestions and comments as necessary. One of the major goals in the supervision was to promote confidence in the home visitor and to develop the respect of the family for them. The therapists remained in the background and did not attempt to take over responsibility for the child from the home visitor and the family. This model could only be implemented if a sincere and close relationship had developed between the co-ordinators and the home visitor. Such a relationship depends on effective human relations and cannot be programmed into existence.

The key role played by the co-ordinator is clearly apparent in the effective programmes in Zimbabwe (Mariga and McConkey, 1987), Kenya (Arnold, 1986) and Malaysia (Jaekle, 1986) where visits, lasting several days, are made to outlying areas by co-ordinators highly committed to the project. Jaekle

(1986) stresses the key part the co-ordinator played in inspiring commitment and dedication in the home visitors. When asked to evaluate the Guyana programme a number of home visitors mentioned the important function played by the co-ordinators in supporting and encouraging their efforts.

The co-ordinator's major task is not that of a lecturer, administrator or legislator but a facilitator of human relations. The goal is to help persons identify their own needs and assist in formulating creative responses to the problems. A crucial consideration in this approach is to know when to stand back and allow clients to take the programme in the direction they choose. The co-ordinators need the humility and the wisdom to know when to stand back and allow local groups to take charge. In doing so the programmes can develop into a community project and not a programme piloted by an outside force.

5.6 Elements for the curriculum

A balance needs to be achieved between adopting a specific set of objectives and maintaining a flexible, open-ended approach. If the model is too definite at the outset it may become a closed systems approach, relying on predictability of outcome. However, the exact role of the home visitor cannot be totally predictable if they are to be effective. An attempt perhaps therefore needs to be made to adopt an approach which emphasizes process not content.

In the Guyana project the home visitors met with the co-ordinators every ten weeks to discuss the programme to date. They began to feel the programme was their own, they became active planners rather than passive recipients. Their ideas were listened to, respected and adopted. Some of the most creative ideas for the project came out of these sessions. The home visitors were challenged to be imaginative and were not merely asked to follow a script. A crucial role of the co-ordinators was to facilitate this process and not simply direct their every step.

In none of the effective programmes reviewed was the home visitor simply following a rigid, prescriptive manual. Indeed, the value of a written manual in the context of a developing country has been questioned. Nevertheless, publications like the WHO Manual have served the key function of stimulating the local production of teaching materials suited to the demands of their own particular culture. This has been achieved in Jamaica (Thorburn, 1990) and the Philippines (Periquet, 1984).

The publication of 'Disabled Village Children' (Werner, 1987) has proven to be a major contribution to this area. Material is included concerning how to work with disabled children and their families and ways of recognizing, helping with and preventing common disabilities. Practical suggestions are offered concerning how to work with the community in promoting the process of social integration and the rights of disabled persons. One section of the book also deals with practical suggestions concerning the preparation of rehabilitation aids with materials available in the rural environment. As Werner states in the introduction, the book was not written by experts and then 'field tested' with community workers, but evolved from community workers and was then reviewed and corrected by experts. The book is a model of clear, concise, well-illustrated material concerning the most common forms of disabilities. The book demonstrates how the resources for assisting disabled persons exist within the community, the family and the disabled persons themselves. The volume is full of excellent drawings and photographs that make it the most visually appealing book in the area.

The Zimcare Trust materials also evolved over several years of field testing. The rehabilitation therapists began by working alongside specialists in the area of adult literacy and audio-visual techniques to prepare suitable materials. A series of 30 illustrated cards form the basis of the teaching programme. The cards, with minimal text, focus on early stimulation, fine and gross motor skills, self-help, language, cognition and survival skills. The cards are prepared as a graded series of tasks. A copy is left with the family of two

or three goals and the appropriate cards. The material is prepared in three languages: English, Shona and Sindebele.

A series of video programmes has also been developed to complement the cards. Fourteen 12-minute programmes have been produced to illustrate the activities on the teaching cards. Practical skills are unlikely to be acquired from books alone. A ready-made teaching package has therefore been produced. Highly experienced trainers are no longer so essential as a good deal of the material is readily available. The videos were all filmed locally using participants on the CBR programme. The materials are very valuable in the training of new staff and in community awareness exercises. Video is proving to be an effective medium for modifying attitudes. Zimcare have therefore produced a curriculum of activities for the parents to use at home. The resources of teaching cards, assessment forms and videos give the families tangible tools for translating knowledge into practice. Moreover, the possibility exists for pyramid training by which those who are trained undertake to train others in the use of the materials, thereby making optimal use of scarce resources. This is a key area which merits more detailed attention. The success of the EDY project in Manchester in utilizing the pyramid model of training could be very usefully examined. McConkey (1986) has clearly demonstrated the value of video in transforming the way we share information with others.

5.7 Establishment of parent associations

Many social and emotional needs of parents can more effectively be offered by participation in an informal voluntary association with other parents of handicapped children. The script for the partnership evolves from the parents themselves.

Few of the parents in the various programmes had met other parents of disabled children before the project began. However, usually by the end of the project the majority had met other parents and found the meeting very helpful in realizing they were not alone with the problem. CBR should be

supplemented by the establishment of a local network of families who could provide mutual support to one another and assume an advocacy role. Such a network could provide a formidable force in working for change in developing countries.

5.8 Financial investment

CBR has been promoted for the illusory reason of economics. The cost of institutional-based rehabilitation has been presented by the World Health Organization to be approximately US $1,000 per person per year. By contrast, CBR is costed at US $9 (Mendis and Nelson, 1983). However, the costs overlooked the expense of training, supervision and referral services.

Whatever gains may be perceived in the programme, one needs to ask whether in view of the resources expended the progress is meaningful and whether the programme can be financed at a level which could be realistically maintained and introduced into other areas.

Cost-effective data on CBR projects is rarely reported in the literature; when it is, the figures per child are often far in excess of the modest US $9 quoted by the World Health Organization. The Guyana programme was financed at approximately US $45 per person per year. Whilst this figure is lower than other CBR programmes, it is still no economic miracle. The figure includes payment for the co-ordinator's time; however, it does not include any estimate of the costs of using institutional-based facilities in the form of special educational provision or surgical intervention. Berman and Sisler (1984) establish that CBR may be no more than 20 per cent cheaper than an institutional-based model of rehabilitation.

Whatever the precise figure, change will only come about when some level of investment is made in the area. One of the goals of Project Projimo in Mexico was eventual self-sufficiency. However, one needs to examine how realistic such an objective is within the context of an improverished rural area. Presently there is no budget for rural

rehabilitation in many countries. Nor are there sufficient funds to meet more than a fraction of the needs of training disabled persons in urban areas. Moreover, the very provision of services, however rudimentary, awakens unmet and unrecognized needs. The true financial implications for an effective CBR programme may therefore be considerable.

If the rationale for embracing CBR is economics then the authorities will be alarmed by the considerable number of newly identified disabled persons who are found to be in need of the more specialized institutional-based services.

5.9 Relationship between CBR and institutional-based rehabilitation services

Institutional-based rehabilitation has sometimes been presented in the form of a caricature. Rather than debating which approach is more effective, effort needs to be invested to see how the approaches could complement one another.

There is a potential danger of CBR providing only superficial services because of limited training, allowing mistakes in the application of poorly understood techniques to go uncorrected for long periods. Moreover, the logistics of attempting to use the limited rehabilitation therapists as supervisors of widely scattered client population is often overlooked.

A programme based on volunteers could do a great deal to increase community awareness and to help get the community and family members sensitized to the needs of children for respect and integration into both family and community activities. However, volunteers alone may be able to do very little in terms of the more technical aspects of rehabilitation.

The debate between institutional-based rehabilitaton and CBR is artificial. In moving away from centre-based services the pendulum has swung too far in the opposite direction. CBR no doubt has great potential; however, without adequate rehabilitation therapists and special educators to supervise

the work, CBR will be no more successful than primary health care has been in comparable circumstances. It is interesting to note that the parents in the Zimbabwe, Kenya and Guyana programmes requested a school or unit to be established for their disabled children in rural areas. The debate between CBR and institutional-based services has therefore overlooked the middle ground, the potential value of intermediate community-based centres.

It is recognized that given the size of the demand and the limited resources available, the education and training needs of the majority of disabled persons cannot be met by special schools and centres alone.

We need to be wary, however, concerning drawing simplistic conclusions. Britain has approximately 500 special schools. Teachers are constantly updating their knowledge and skills and introducing innovations in content and method. Such a valuable resource cannot be dismantled easily. In developing countries the services may not be so developed. It is perhaps there where a new pattern of services can be most easily established.

A more detailed analysis of the potential contribution of community-based centres with mid-level trained workers, run by the community, and using local materials is necessary. Such centres could provide a valuable training base for parents and professionals from other areas. The available special education provision could be used as resource centres for outreach programmes, such as providing in-service training for ordinary teachers, outreach support services for families and disabled children or for providing educational support to pupils with special needs in the ordinary school.

Unfortunately, CBR and institutional-based services have been regarded as mutually exclusive when in reality they are complementary. The debate has become emotional and views polarized. Therapists, educators and planners in developing countries have the challenge of reconciling the debate.

The appropriateness of CBR as opposed to institutional-based services depends on a number of factors including: the level of development in the country, population structure, consciousness of disability as a priority area, level of literacy, the spirit of volunteerism and sense of community.

6. CONCLUSION

Follow-up data on the various projects would be necessary to see how well the parents have been trained and how motivated the community is to maintain the gains on their own. It may be too early to say how permanent the changes in behaviour are. However, a number of the projects have demonstrated what can be achieved, at low cost, to create not only better opportunities for the child, but a sense of hope on the part of parents that they can play a significant role in the development process. The community has become more aware of disabled persons in their midst and has often played a major role in planning ways of meeting their needs. For those who require more specialized help institutional-based services have become more relevant and accessible. In the final analysis, it is people that make a programme work. The CBR programmes have been effective in mobilizing and inspiring a group of workers from the community to take on the challenge of working with disabled children.

CBR has presented a new approach to rehabilitation to policy-makers, planners and community leaders in many countries. The programmes have trained a dedicated and competent cadre of home visitors who may continue their work formally and informally with other children.

All the children gained something, some gained more than others. Some effectively made use of what was offered, others may soon forget. If the goal is to serve, many of the families have been served well and the projects were successful.

As the International Decade of the Disabled closes it is clear that the challenge of meeting the needs of disabled

persons has yet to be met. The traditional methods can do little more than scratch the surface; a radical reappraisal of our roles as professionals, as promoters of community development, is necessary. The CBR approach offers such a role. If we lack the vision and courage to tread new paths, then the danger is that more declarations will be written, more slogans devised, and still 98 per cent of the disabled population will remain totally unaware of the international concern being voiced on their behalf.

APPENDIX

Examples of CBR programmes from around the world

The following examples have no pretence to be an exhaustive description of CBR projects internationally. However, they offer an illustration of some of the strengths and limitations of the approach and have been selected, in part, for the ease with which the interested reader could learn more about the programmes. They are presented in alphabetical order.

1. Guyana

Two-year pilot project with 59 pre-school disabled children with a range of disabilities living in rural areas of Guyana. Volunteers and local teachers were used as the home visitors. The home visitors worked with a family member in the home of the disabled individual. A significant level of involvement has been recorded for the programme using volunteers. A detailed evaluation is available which examines the impact of the programme from the perspective of the child, family and community. Analyses both strengths and limitations of the approach. Examines what 'success' means in terms of rehabilitation. Three-year expansion of the programme now in process. Original project funded by the Canadian International Development Agency and the Universities of Guyana and London.

References:

O'TOOLE, B.J. 1990. Development and evaluation of a community-based rehabilitation programme for pre-school children in Guyana. Chapter 16 in Thorburn, M. and Marfo, K. (op. cit.).

O'TOOLE, B. 1988. Step by step, VHS video of Guyana CBR programme, available in NTSC and PAL.

Contact:

Dr Brian O'Toole, 18 L'Esperance, Canal #1, WBD, Guyana, South America.

2. Jamaica

'3D' Project working with 600 disabled persons of all ages and aetiologies. Objective is to provide integrated community-based services to the disabled. Provides early identification of children at risk of delayed development and offers advice and follow-up and intervention mainly through a home-based programme carried out by parents. Funded by Christoffel Blindenmission of Germany. A very successful programme that has continued to grow and develop by mobilizing resources from the local communities.

References:

THORBURN, M. 1982. Community aides for disabled pre-school children in Jamaica. Assignment children, 53/54.

_____. 1990. Case-studies of programmes in six countries, Chapter 4 in Thorburn and Marfo (op. cit.).

PATH NEWSLETTER, newsletter that reviews CBR initiatives internationally, available from NARCOD, P.O. Box 220, Kingston, 10, Jamaica.

Contact:

Dr Molly Thorburn, '3D' Projects, 14 Monk St., Spanish Town, Jamaica, West Indies.

3. Kenya

Action Aid project which grew out of a local self-help group which ran a small school for disabled children in the capital and who recognized the need to move out into the rural areas. Parents learnt methods of helping to facilitate the child's development. The programme is now being used as a training base for outlying areas. The programme was a major step out of isolation for the disabled persons and their families. Home visitors were school-leavers from the community. Programme independently evaluated. The wisdom of only relying on volunteers is questioned. Home visitors well supported by the programme co-ordinator, such supervision was regarded as essential for up to one year to develop the necessary knowledge, experience and enthusiasm for the project. It was felt that after this time a less intensive model of supervision could be used. Very detailed, independent, thorough and critical analysis of the Action Aid project in Kenya is offered in the AMREF report.

References:

AMREF. 1987. The Nairobi family support services: A community-based rehabilitation project. African Medical and Research Foundation, Nairobi, Kenya.

ARNOLD, C. 1986. Reaching families in rural areas. Paper presented at the 9th International Conference of the International League of Societies for Persons with Mental Handicap (ILSMH), Rio de Janeiro, Brazil, 21-29 August 1986.

Contact:

Action Aid Kenya, P.O. Box 42814, Nairobi, Kenya.

4. Malaysia

Society for the Blind recognized the limited provision for the visually impaired in Malaysia and mounted an outreach

programme. The evaluators noted very good rapport between the programme personnel and the families of disabled persons and the blind persons themselves. This was regarded as a key factor in the effectiveness of the programme. Detailed evaluation carried out. Individual rehabilitation programmes were developed for each person. These were devised by the field workers in close collaboration with the field supervisor. Services for the visually impaired were therefore significantly expanded. Considerable practical benefits to the disabled persons and their families were recorded by independent evaluators. Intensive six-week training programme before beginning work with the families. Throughout the programme field workers given on-the-job training. One-year follow-up of each client. Visits decreased once client demonstrated support no longer necessary. Support gradually phased out with a formal case closure exercise. The Jaekle report offers a valuable and detailed analysis of a CBR programme with blind persons which offers insights concerning the essential elements of a successful programme. Good information on how to evaluate a service.

Reference:

JAEKLE, R.C. 1986. Rehabilitation services for the rural blind pilot project in Pahang state. Malaysian Association for the Blind and the Royal Society for the Blind.

5. Mexico

Project Projimo grew out of a village-run primary health care service which highlighted the needs of disabled persons in the rural areas. Projimo now trains persons from other villages in how to overcome disability. Objective is to give the disabled person and their family the understanding and skills they need to help the disabled person reach their full potential. Projimo means 'good friend' or 'neighbour' in Spanish. High degree of community involvement in the project. Projimo run by disabled persons themselves. Child-to-child activities in local schools raise the consciousness of children concerning

the needs of their disabled colleagues. Independent evaluation. Project given high ratings by families of disabled persons. Examines the concept of 'success'. Emphasizes the need to adopt a broader concept of evaluation, to examine social, affective and interpersonal change. Projimo offers an excellent example of a supportive model of supervision. The role of the therapist is to 'accompany' the home visitor and not dominate, thereby facilitating the growth of the home visitor and nurturing the respect of the family, the disabled individual and the community for the worker.

References:

PROJECT PROJIMO. 1986. Project Projimo. A village-run rehabilitation programme for disabled children in Mexico. Hesperian Foundation, Palo Alto, California.

Attractive, illustrated and detailed introduction to the pioneering work of the Projimo community.

WERNER, D. 1987. Disabled village children. Palo Alto, California: Hesperian Foundation.

Excellent, detailed, illustrated and highly readable Manual on how to help disabled children. Written in the style of 'Where there is no doctor', and will no doubt become equally as indispensable all over the world. An essential book. Suggestions for working with disabled persons and their families, recognizing, helping with and preventing common disabilities. Book grew out of the experience of Werner and others which was acquired over a decade of working in the field.

VILLEGAS, J.C.H. 1985. A study of a community-based rehabilitation programme in Mexico. Dissertation for M.Sc in Maternal and Child Health, Institute of Child Health, University of London.

Independent and balanced evaluation of the Projimo programme, presented in a readable manner.

Contact:

Martin Mercado, Ajoya, San Ignacio, Sinaloa, Mexico.

6. Pakistan

Jaffar and Jaffar are very critical of the concept of CBR. Critical of the work performed by the home visitors. None of the home visitors in this project did even half of the activities. Their limited training and their lack of any professional identity is regarded as the reason for their lack of effectiveness. Detailed and very honest account.

Reference:

JAFFAR, R. and JAFFAR, R. 1990. The WHO CBR approach; programme or ideology. Some lessons from the CBR experience in Punjab, Pakistan. Chapter 15 in Thorburn and Marfo (op. cit.).

Contact:

Rafiq Jaffar, 14/E-IV, Model Town, Lahore, Pakistan.

7. Philippines

Valdez programme highly based on WHO approach. Widely regarded as one of the most successful illustrations of the approach. Community involvement widened to encompass mini-Olympics, leadership training programmes, cultural programmes. Highly committed home visitors who are recognized within their communities.

Berman and Sisler's evaluation of a programme with blind persons is an excellent attempt at evaluation and cost-effectiveness in this area. Very useful economic analysis of the relative strengths of the CBR and institutional-based approaches. Presents evidence that CBR is no economic miracle.

References:

BERMAN, P.A., and SISLER, D.G. 1984. Rehabilitation of the rural blind. An economic assessment of a programme in the Philippines 1978-83. Hellen Keller International.

PERIQUET, A.O. 1984. Community-based rehabilitation: the experience of Bacolod, Philippines and the Asia and Pacific region. Monograph 26, World Rehabilitation Fund, New York.

Overview of Philippines programme with sufficient detail to understand what happened on the programme.

VALDEZ, J.S. 1984. Community-based rehabilitation services, provision in poverty stricken and rural areas. Negro Occidental Rehabilitation Foundation, Bacolod City, Philippines. (Mimeo).

Report of a CBR programme that has now become one of the model projects of the WHO approach to CBR.

Contact:

Mrs Joy Valdez, Negro Occidental Rehabilitation Foundation, Bacolod City, Philippines.

8. Zambia

Ambitious plan to reach the disabled children of the nation. Goal was to establish a foundation for nationwide services. Systematic screening programme and reporting centres planned to assess the needs of the disabled children. Goal was to establish district rehabilitation teams with multidisciplinary members. Specialist teams would then check the diagnosis, arrange necessary operations and offer in-service training. However, the results were very variable, ranging from some highly encouraging results to other cases where very little was achieved. Home visitors felt they needed more supervision and ongoing training.

Reference:

SERPELL, R. 1986. Specialized centres and the local home community: children with disabilities need them both. International Journal of Special Education, 1, 107-127.

9. Zimbabwe

Programme run by Zimcare Trust, the organization responsible for the welfare of the mentally handicapped children in Zimbabwe. Zimcare Trust realized that the existing services were not meeting the needs of those in rural areas. National Disability Survey of 1981 revealed thousands of handicapped children to be living in rural areas with no help. Therefore they began an outreach programme to help disabled children within their own communities. Effective partnership formed with a variety of agencies already working in rural areas: Red Cross, Cheshire Home, Ministry of Health. An effective infrastructure already existed and was well accepted in the rural areas thereby allowing the new programme to be speedily implemented and effectively integrated into existing community work. Programme utilized and stimulated an existing infrastructure. Zimcare Trust has shown vision and creativity in effectively utilizing existing resources. Detailed independent evaluation conducted. Materials evolved over several years of field testing. Series of cards with a minimal of text and clear illustrations. Cards focus on early skills in a graded series of tasks. These are complemented by a series of excellent videos, shot on location, which illustrate the activities on the cards. The programme offers a ready-made teaching package with a curriculum of activities for parents to use in their home.

Reference:

MARIGA, L. and McCONKEY, R. 1986. Home-based learning programmes for mentally handicapped persons in rural areas of Zimbabwe. Paper presented at the 9th ILSMH Conference, Brazil.

Contact:

Mrs Lilian Mariga, Zimcare Trust, Box BE 90, Hararo, Zimbabwe.

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ACTON, N. 1983. World Disability, the need for a new approach. In Shirley, O. A cry for health: poverty and disability in the developing world. The Third World Group for Disabled Persons.

Offers an overview of the challenge in the area of disability in the coming years.

GREENWOOD, J.G. 1985. Disability dilemmas and rehabilitation dilemmas, Social Science and Medicine, 20, (12), 1241-1252.

Stresses that there are significant shortcomings in service provision in the West too. The need for innovative forms of service provision is not solely an issue for developing countries. Also introduces some practical problems inherent in the CBR approach.

HELANDER, E.; MENDIS, P.; NELSON, G. and GOERDT, A. 1989. Training disabled persons in the community. WHO, Geneva.

The WHO Manual on CBR deals with the major areas of disability, the training of local supervisors, the involvement of the community and advice for schoolteachers.

MENDIS, P. and NELSON, G. 1983. Intermediate-level supervision of community-based rehabilitation. WHO RHB/83.4.

MILES, M. 1985. Where there is no rehab plan: a critique of the WHO scheme and some suggestions for future directions. Peshawar, Pakistan.

To date, the major critique of a number of assumptions underlying CBR. Based on his decade of experience in the rehab field in Pakistan.

HINDLEY-SMITH, R. 1981. Helping disabled people at home; a new approach to rehabilitation. PAHO Scientific Publication, 411.

Offers an overview of an early attempt at CBR in a rural area of Mexico.

ILSMH. 1990. Education for All, ILSMH, Belgium.

Clear analysis of the need to integrated children with special needs into the regular school system.

MOMM, W. and KONIG, A. 1989. Experiences and reflections on a new concept of service provision for disabled people. ILO, Geneva.

A detailed critique of the philosophy of CBR based on a decade of ILO experience.

McCONKEY, R. 1986. Working with parents: a practical guide for teachers and therapists. Croom Helm, London.

Excellent overview of the area with a wealth of practical information. Movement from slogans to practice.

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Copies of 'CBR News', which is a newsletter that documents CBR innovations around the world, are available from the CBR Unit, Institute of Child Health, University of London, 30 Guilford St., London. Information on the training programme for CBR workers that the University of London offers can also be obtained from this address.